

**THE ASSOCIATION BETWEEN PREMATUREITY, MOTOR FUNCTION AND HEALTH  
RELATED QUALITY OF LIFE AMONG LEARNERS IN THE FOUNDATION PRIMARY PHASE**

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Signed on 13 March 2017 in Bloemfontein.

Signed by candidate
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Henriette Tredoux (Oosthuizen)

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*‘Challenges are what make life interesting and overcoming them is what makes life meaningful.’*

*– Joshua J. Marine*

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*‘Education is the most powerful weapon you can choose to change the world.’*

*– Nelson Mandela*

## SUMMARY

**Introduction and Aims:** Children born prematurely ( $\leq 36$  weeks gestation) are at risk of poor developmental outcomes and are more likely than their full-term (FT) peers to have behavioural, physical and/or cognitive limitations. In order to deliver effective interventions, therapists need to have a sound understanding of the problems experienced by children who were born prematurely. Presently, very little is known about the functional problems of young school aged children, living in the Free State province of South Africa, who were born prematurely.

**Methodology:** This study was conducted in 15 randomly selected schools located within in a 100 km radius of Bloemfontein. Two groups of children in grades R, 1 and 2 (age range: 5-8 years) were recruited, the first group (PREM group) consisted of children having a history of premature birth ( $\leq 36$  weeks). The second group consisted of full term children (FT group) who were matched for age and gender to the first group. The PREM group was categorised into three subgroups according to prematurity status: late premature (34-36 weeks, LP), moderate (MP) to very premature (29-33 weeks, VP) and extremely premature ( $\leq 28$  weeks, EP).

A self-designed questionnaire was used to record demographic and medical information obtained from parents. The questions were related to antenatal factors, birth and medical history of the child. The Movement Assessment Battery for Children second edition (MABC-2) and MABC-2 Checklist were used to evaluate functional motor problems in children. The European Quality of Life 5 Dimension Scale- Youth version (EQ-5D-Y) was used to determine the Health Related Quality of Life of the children and the Strengths and Difficulties Questionnaire (SDQ) was used to describe the behavioural and emotional status of each child according to their parents and teachers.

Ethical approval was obtained from the University of Cape Town Research Ethics Committee (HREC REF: 694/2014) and permission to conduct the study within schools was granted by the Free State Education Department. Informed consent and assent was obtained. Parents were interviewed by a research assistant using the self-designed questionnaire. A different researcher then tested all children using the MABC-2 and assisted each child to complete the EQ-5D-Y. The parents and teachers each completed the SDQ and teachers completed the MABC-2 checklist.

Statistical analysis was conducted using SAS<sup>®</sup> Version 9.4 and STATISTICA 10. The data were summarized using descriptive statistics (i.e. number of available data (n), mean, and standard deviation, minimum, median and maximum). The Mann Whitney U test was used to compare groups (PREM vs FT groups) and the Chi-square test was used to determine any association between groups and

descriptive variables. Comparisons between prematurity subgroups were conducted using the Kruskal-Wallis ANOVA.

**Results:** 122 children participated in this study: 61 FT children and 61 PREM children. The PREM group consisted of 23 children who were classified as late premature, 27 who were moderate to very premature and 11 children who were extremely premature

There were no differences between groups in terms of age ( $U = 1760$ ,  $z = -0.51$ ,  $p = 0.610$ ), gender ( $\chi^2 = 0.03$ ,  $df = 2$ ,  $p = 0.86$ ), grade level ( $\chi^2 = 0.386$ ,  $df = 3$ ,  $p = 0.98$ ) and socioeconomic status [as defined by mothers level of education ( $\chi^2 = 3.79$ ,  $df = 2$ ,  $p = 0.15$ ) and school quintile ( $\chi^2 = 5.22$ ,  $df = 2$ ,  $p = 0.07$ )]. Differences were found in terms of maternal age at delivery (PREM = 31.9 years [ $SD=5.2$ ] vs. FT = 29.02 years [ $SD = 3.5$ ]  $df = 120$ ,  $t = -3.61$ ,  $p < 0.001$ ).

As expected, the PREM group had a significantly lower birthweight compared to the FT group (PREM = 2201g [ $SD = 748$ ] vs. FT = 3132g [ $SD = 406$ ],  $df = 120$ ,  $t = 8.54$ ,  $p < 0.001$ ). 96.7% of those in the PREM group were born via C/section ( $p < 0.0001$ ). Apart from one case of respiratory distress, the FT group reported no neonatal complications. As expected, more candidates in the PREM group were more frequently hospitalised ( $\chi^2 = 34.605$ ,  $df = 2$ ), and 7 cases of CP were reported. The APGAR scores were significantly different between FT and PREM groups at 1min ( $p < 0.0001$ ) and 5min ( $p < 0.0001$ )

Regarding **motor performance**, there was a significant difference in MABC-2 Total Standard Scores (MABC TSS) ( $U = 1425.0$ ,  $z = 2.23$ ,  $p = 0.026$ ) and the MABC-Checklist Total Motor Scores ( $U = 1016.5$ ,  $z = -4.32$ ,  $p < 0.0001$ ) with FT group performing better and reporting less functional motor problems than the PREM group.

Regarding **HRQoL**, we found that groups were also significantly different in terms of the Mobility domain of the EQ-5D-Y with the Prem group reporting more problems than the FT group ( $\chi^2 = 6.31$ ,  $df = 1$ ,  $p = 0.012$ ). No differences were found between groups with regard to the Looking After Myself ( $\chi^2 = 2.03$ ,  $df = 1$ ,  $p = 0.153$ ), Usual Activities ( $\chi^2 = 0.00$ ,  $df = 1$ ,  $p = 1.0$ ), Worried/Sad/Unhappy ( $\chi^2 = 1.22$ ,  $df = 1$ ,  $p = 0.541$ ), and Pain/Discomfort ( $\chi^2 = 3.59$ ,  $df = 1$ ,  $p = 0.165$ ) domains.

In terms of **emotional-behavioural status**, we found no differences between the two groups in terms of Parent Total Difficulties scores ( $U = 1791.50$ ,  $z = -0.351$ ,  $p = 0.725$ ) as well as Teachers Total Difficulties Scores ( $U = 1518.0$ ,  $z = -1.751$ ,  $p = 0.08$ ). However, the FT group scored lower than the PREM group on the emotional domain ( $U = 1404.0$ ,  $z = -2.33$ ,  $p = 0.02$ ) indicating less problems and higher on the prosocial domain ( $U = 1335.0$ ,  $z = 2.68$ ,  $p = 0.007$ ) indicating more positive factors in

this group. On examination of the PREM sub groups, we found no differences in Parent Total Difficulties Score between groups ( $p = 0.377$ ).

When we compared parent versus teacher SDQ scores, 45 (73.8 %) cases where the parent and teacher were in agreement with the “normal” assigned score. In addition, there were 2 (3.3 %) cases where the parent and teacher respectively assigned a score of “abnormal” and “borderline”. Regarding the Impact scores, parents/caregivers reported that the difficulties (emotional, conduct, hyperactivity, peer and prosocial problems) did not have an impact on a child’s friendship ( $p = 0.2889$ ), classroom learning ( $p = 0.2325$ ), leisure activities ( $p = 0.3585$ ) or their home life ( $p = 0.1248$ ). In contrast, teachers’ responses indicated that the difficulties had an influence on classroom learning ( $p = 0.0030$ ) but not friendships ( $p = 0.2374$ ).

**Discussion:** The late premature group made up a bigger proportion of the premature group. This correlates with the PPIP report, where the same trend was noted for the South African premature population (Pattinson, Saving Babies [PPIP], 2012-2013; Kalimba & Ballot, 2013).

Findings from this study correlated with literature on PREM children being more at risk of decreased motor function when compared to FT peers (Hack et al., 2002; Chyi et al., 2008; Stephans & Vohr, 2009; Van Baar et al., 2009; Hornby & Woodward, 2009; Van Baar et al., 2013). Fine motor skills is essential in a child’s daily activities and very important to function at school. This study indicated a deficiency within fine motor and balance domains within the PREM group.

Maternal age surfaced as predictor of motor performance as younger mothers ( $< 19$  years) have an increased risk of low birth weight and premature infants (very and extremely premature) (Schempf, Branum, Lukacs & Schoendorf, 2007; Gibbs, Wendt, Peters & Hogue, 2012; Kalimba & Ballot, 2013; Fall, Sachdev, Osmond, Restrepo-Mendez, Victora, Martorell, Stein, Sinha, et al., 2015; Benli, Benli, Usta, Atakul, Koroglu, 2015). Literature on older mothers ( $\geq$  age 35) also showed an increased risk towards premature birth (moderate and very premature) with more medical conditions (such as hypertension and diabetes)-this was not the case in this research (Schempf et al., 2007; Gibbs et al., 2012; Kalimba & Ballot, 2013; Fall et al., 2015; Benli et al., 2015), however it is reported that PREM infants from older mothers show somewhat better outcomes of infants later in life (Schempf et al., 2007; Gibbs et al., 2012; Kalimba & Ballot, 2013; Fall et al., 2015; Benli et al., 2015).

Other findings from this research indicated that, from the teachers’ perspectives, PREM children showed a greater tendency towards emotional and prosocial behaviour impairments, than the FT population. This aligns with literature where premature infants are mentioned to be more susceptible to behaviour performance problems at school-age (Kerstjens et al., 2012; Bos et al., 2013; Moreira et al.,

2014). In this research, the extremely premature group had more behavioural problems which had an impact on these children's leisure activities, peer, and classroom learning.

**Conclusion:** Our findings suggest that PREM children have more motor problems than FT children and that the very preterm group showed the highest risk for motor problems. Maternal age also indicated to be an influencing factor where mothers younger than 19, as well as mother over 35, both indicated a risk for premature birth, resulting in low birth weight. Other risk factors influencing function in the PREM, apart from low birth weight, indicated by the results were factors like respiratory distress, apnoea, haemorrhaging and the exposure to post-natal steroids. According to teacher's perceptions, the children in the PREM group, tended to show more behavioural and emotional problems than those of the FT sample.



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## ABBREVIATIONS

PREM	Premature
FT	Full term
MP	Moderate Preterm
LP	Late Preterm
VP	Very Preterm
EP	Extremely preterm
ADHD	Attention Deficit Hyperactivity Disorder
CP	Cerebral Palsy
DCD	Developmental Coordination Disorder
DF	Degrees of Freedom
ELBW	Extremely low birth weight
EPT	Extremely preterm
GA	Gestational Age
HRQoL	Health Related Quality of Life
LBW	Low birth weight
MABC2	Movement Assessment Battery for Children Second Edition
NDT	Neuro Developmental Therapy
NEC	Necrotizing Enterocolitis
NICU	Neonatal Intensive Care Unit
OT	Occupational Therapist
PDA	Patent Ductus Arteriosus
PPIP	Perinatal Problem Identification Programme
PT	Physiotherapist
SD	Standard Deviation
SES	Socioeconomic Status
SGA	Small for Gestational Age
ST	Speech Therapist
VLBW	Very low birth weight
WHO	World Health Organisation
WMA	World Medical Association
GMFCS	Gross motor function classification system

# 1 INTRODUCTION

Advances in neonatal care have contributed to reducing mortality and decreasing the severity of neurodevelopmental outcomes in children born prematurely. It is known that children with a history of premature birth have variable outcomes in terms of their functional abilities. Some children go on to develop conditions such as cerebral palsy (CP), while others may have moderate or mild cognitive or motor problems such as delayed attainment of age-appropriate motor skills or behavioural and attention problems (De Regnier, 2008; Guerra et al., 2013; Spittle and Orton, 2014; Mansson and Stjernqist, 2014). According to the Perinatal Problem Identification Report (2012-2013), 8 /100 babies are born prematurely in South Africa (Pattinson, 2013; Blencowe et al. 2012).

Certain prenatal and perinatal factors may increase the risk of adverse developmental outcomes for children born prematurely. These risks include exposure to infections during pregnancy, maternal co-morbidities such as diabetes and hypertension, advanced maternal age, low socio-economic status, multiple pregnancies, smoking, substance abuse and maternal obesity (Nosarti, Murray, Hack, 2010; Kerstjens et al., 2013). Postnatal factors such as health complications\_(such as respiratory distress syndrome, chronic lung disease-bronchopulmonary dysplasia, injury to the intestines, a compromised immune system, cardiovascular disorders, hearing and vision problems, and neurological insults), frequent hospitalisations, and inadequate post-discharge care, further impact on the development of a child born prematurely (Behrman and Butler, 2007; Nosarti et al., 2010). Some research in South Africa revealed that infants tend to experience more impairments and handicaps at a younger age, but seem to slightly improve with age (Cooper, Sandler, 1977; Deeny et al., 1987; Thompson et al. 1993), although more recent research from Burger et al (2011) disagreed with the previous 80's research as these impairments and handicaps did not improve when age (Burger, Frieg, Louw, 2011).

## 1.1 Prematurity categories and development

More premature births tend to fall in the 34-36 week gestation (late preterm-LP) period (Raju et al. , 2006; Woythaler et al., 2011). However, LP children are still considered by health care professionals as being at low risk for morbidity. These children might present with milder problems affecting either multiple or singular domains of function, such as motor, language and cognitive development (Raju et al., 2006; Chyi et al., 2008; Van Baar et al., 2013). Van Baar et al. (2013) and Chyi et al. (2008) share their concerns regarding LP children and their long term outcomes, as this group shows the highest survival numbers of premature infants (Van Baar et al., 2013). It is assumed that this group's development is closer to the full term group than the premature group and for this reason their problems

are sometimes overlooked (Raju et al., 2006; Chyi et al., 2008; Woythaler et al., 2011; Van Baar, et al., 2013).

Literature indicates that moderately premature (32-34 weeks-MP) infants, show a higher incidence of developmental, behavioural and social problems in the foundation school phase compared to LP infants which leads to the need for further educational assistance (Kerstjens et al., 2013; Cserjesi et al., 2012). MP infants therefore are also a concern to the education system in terms of their greater special educational needs (such as poor reading skills and math scores) (Chyi et al., 2008).

Severe disability, as seen in very (29-33 weeks-VP) and extremely premature ( $\leq 28$  weeks-EP) is often directly linked to disrupted early brain development and structural damage to the developing brain (Du Plessis and Volpe, 2002; De Regnier, 2008; Alvarado-Guerrero et al., 2011; Mansson and Stjernqist, 2014). With this in mind, concerns regarding the long term impact of premature birth still need to be investigated in the South African context

## **1.2 Impact of prematurity at school age**

Children who do not present with severe physical and cognitive impairments in the early developmental period may be admitted to mainstream schools. However, as they progress through the foundation phase, teachers and parents may detect problems that interfere with their functioning in the classroom or on the playground. Of particular concern to parents, teachers and therapists, are the problems related to motor performance (such as fine and gross motor activities, developmental coordination disorder), cognitive function (e.g. poor language development, and poor cognitive reasoning) and behaviour (e.g. attention deficit disorders) (Bracewell and Marlow, 2002; Guerra et al., 2013; Spittle and Orton, 2014).

Studies suggest that children born prematurely have poor motor performance and behavioural problems which affect their school function and health related quality of life (HRQoL) (Alvarado-Guerrero et al., 2011; Oberg et al., 2012). While children with severe forms of disability may be easily identified, children with milder problems are often overlooked (Raju et al., 2006; Chyi et al., 2008; Van Baar et al., 2013). In light of large numbers of children born prematurely, who are entering mainstream schools, and taking into consideration the neurodevelopmental problems experienced by this group, it is imperative that physiotherapists have a sound understanding of the long-term impact of premature birth on the child, his/her family, and on the health and education systems.

## **1.3 Rationale for this study**

Knowledge of the problems experienced by children born prematurely, can also help therapists design applicable problem-specific rehabilitation programmes, specific training models, and practice guidelines. Research studies suggest that early assessment, early therapeutic intervention and



continuous monitoring of children who were born prematurely may contribute to improving their physical and cognitive development, minimise social problems and improve the quality of life in the later stages of their lives (Alvarado-Guerrero et al., 2011; Oberg et al., 2012; Fernandez, Gomez, Perez, 2012).

#### **1.4 Aims and objectives of this study**

The aims of this study were, *firstly* to compare the motor performance, HRQoL and emotional-behaviour profile of children (in grades R, 1 and 2; age range: 5-9 years) who were born prematurely and at full term. *Secondly*, to compare performance of children born at different stages of prematurity (late, moderate and extremely premature). *Finally*, to establish the extent to which certain neonatal and maternal factors (identified in the literature) were associated with performance outcomes at primary school age.

The specific objectives were to:

1. Describe and compare the neonatal medical history and maternal medical history of the two groups (PREM and FT) as determined by a retrospective review of medical records and hence, determine if there are a link between certain neonatal and maternal factors in performance outcomes.
2. Determine if there was a significant difference in motor performance and motor function between groups (PREM and FT groups), as measured by the Movement Assessment Battery for Children-second edition (MABC-2) and the Movement Assessment Battery for Children- Checklist.
3. Determine if there was a significant difference in HRQoL between PREM and FT groups, as measured by the European Quality of Life-5 Dimension Scale-Youth Version (EQ-5D-Y).
4. Determine whether there was a significant difference in behaviour, as reported by teachers and parents between PREM and FT groups, as determined by the Strengths and Difficulties questionnaire (SDQ).
5. Examine the difference in motor performance, HRQoL and emotional-behavioural profile in three PREM groups.

#### **1.5 Significance of this study**

The purpose of this study is to raise awareness and provide insight into the functional motor performance, behaviour and HRQoL of children born prematurely within a school setting. It is anticipated that the information gained may be used by parents, educators and therapists to help these children access the support services they need. In addition, this study aims to raise awareness of the various maternal and antenatal risk factors associated with premature births in the current context.

A meta-analysis on cognitive and behavioural problems in school-aged children who were born preterm show that the immature brains of premature infants have the ability to modify their own structure and function. This promotes functional recovery (called neuroplasticity) following changes within the body or the external environment (Bhutta et al., 2002; Luciana, 2003). The findings emerging from this research study could help to advocate for strategies and programmes to promote the optimal brain development of these children (De Regnier, 2008). Therefore, it can clearly be seen that identification of problems related to prematurity, and subsequent intervention may support children born prematurely in reaching their potential.

## 2 LITERATURE REVIEW

### 2.1 Defining Prematurity

The duration of a normal pregnancy is considered to be 40 weeks (280 days) from the date of conception. A baby is regarded as premature when he/she is born before 37 weeks gestation (Bhutta et al., 2002; Lubbe, 2008). *Late* prematurity refers to an infant born between 34-36 weeks gestation, *moderately* premature infants are born between 29-33 weeks and *extremely* premature infants are born  $\leq 28$  weeks (Bhutta et al., 2002; Lubbe, 2008).

The aforementioned ‘stages’ of prematurity are based on the gestation period. However, prematurity can also be linked birthweight. Most premature infants tend to be below the normal birth weight which is considered to be approximately 2500g (Bhutta et al., 2002; Lubbe, 2008). These definitions are explained in Table 1. Survival rates for premature infants are reported to change in relation to gestation and birth weight (Nosarti et al., 2010).

**Table 1: Classification of infants according to birth weight and gestational age**

Definition	Gestational Age	Weight
<u>Gestational age:</u>		
Full term	$\geq 37$ weeks	$> 2500$ g
Premature	$< 37$ weeks	
<b>Late premature (LP)</b>	34-36 weeks	
<b>Moderately (MP) to very premature (VP)</b>	29-33 weeks	
<b>Extremely premature (EP)</b>	$\leq 28$ weeks	
<u>Birth weight:</u>		
<b>Low birth weight (LBW)</b>		1500 g - 2500 g
<b>Very low birth weight (VLBW)</b>		$< 1500$ g
<b>Extremely low birth weight (ELBW)</b>		$< 1000$ g

(Bhutta et al., 2002; Lubbe, 2008; Levene, Tudehope, Sinha, 2008; Nosarti et al., 2010).

### 2.2 Statistics

A report from the World Health Organisation (WHO) and partners indicated that worldwide preterm birth figures had increased over the past 20 years and that one in ten live births were premature. (Blencowe et al., 2012, WHO, 2014). Advances in obstetric and neonatal care with improvements in discharge management and rehabilitation have resulted in an increased number of premature survivors (Withfield, Granau, Holsti, 1997; Msall and Park, 2008). Blencow et al. (2012) reported that more than 60% of preterm babies worldwide were born in south Asia and sub-Saharan Africa. This is significant as the low and middle income countries in these regions have limited healthcare resources to support

these infants. Currently, about 70 % of preterm births are LP, 13 % are MP and 17 % VP. The increase in preterm births between 1990 and 2006 is mostly accounted for by the rise in LP births, which (as a proportion of all births) rose from 7, 3 to 9, 1 % (Petrou, Henderson, Bracewell, Hockley, Wolke, Marlow, 2006; Loftin et al., 2010; Blencowe et al., 2012; WHO, 2014).

When considering the survival rate in South Africa, the annual Perinatal Problem Identification Programme (PPIP) report of 2012/2013, listed an increase in the number of extremely low birth weight babies with a further increase in the number of low birth weight survivors (Pattinson, Saving Babies [PPIP], 2012-2013). The report estimated eight out of 100 babies in South Africa to be preterm. This rising number is due in part to efforts by neonatology teams who have used innovative equipment to increase the survival of premature babies (Bateman, 2013). In addition, changes in drug therapy (surfactant and antenatal steroids), mechanical ventilation and primary health care have contributed to more favourable morbidity rates in inside tertiary care centres in South Africa, with no statistical improvement in mortality rates outside tertiary care centres (Pattinson, Saving Babies [PPIP], 2012-2013; Ballot et al., 2012).

The Saving Babies (PPIP) report of 2012-2013 estimated that preterm birth rates in South Africa made up about 8 per cent of a total of 1 057 000 live births (Pattinson, Saving Babies [PPIP], 2012-2013. In comparison with international rankings, this number places South Africa 128th globally (Blencowe et al., 2012; Loftin et al., 2010; Lloyd and de Witt, 2013). Although these figures confirm the survival of more extremely premature and low birth weight infants in South Africa in resource-limited and tertiary settings, all survivors may therefore be in need of specialised rehabilitation (Lloyd and de Witt, 2013).

## **2.3 Risk factors for developmental problems associated with premature birth**

Certain maternal factors may increase the risk of delivering a premature baby and may be associated with increased risk for adverse development later in life. Some of the more important risks include medical conditions (such as diabetes, infections, etc.), maternal age (younger than 18 and older than 35), socioeconomic status (and ethnicity), multiple pregnancies, smoking, substance abuse (including illegal drugs), maternal obesity (Nosarti et al., 2010; Kerstjens et al., 2013) and women who have delivered preterm before, or who have experienced preterm labor before, are considered to be at high risk for preterm labor and birth (Nosarti et al., 2010; Kerstjens et al., 2013; Ryan and Black, 2015).

### **2.3.1 Perinatal factors**

Perinatal risk factors (factors associated with the birth/delivery process) are linked to long term dysfunctions and impairments, depending on the severity/intensity of the perinatal conditions (Potharst et al., 2013). The type and duration of delivery can lead to birth injuries, which might be temporary or have long term outcomes on infants (Schiariti et al., 2008; Levene et al., 2008; Nosarti et al., 2010;

Potharst et al., 2013). The different types of injuries occur from the use of tools to assist in delivery, administering the wrong medication, mishandling the infant (such as broken bones, lacerations, or skull fractures), and injuries related to stress, high blood pressure, or hypertension (Schiariti et al., 2008; Levene et al., 2008; Nosarti et al., 2010; Potharst et al., 2013). The provision of antenatal or postnatal corticosteroids in uncontrolled, high dosages will interfere with neurodevelopmental outcomes (Schiariti et al., 2008; Levene et al., 2008; Nosarti et al., 2010; Potharst et al., 2013).

#### **2.3.1.1 Medical Complications associated with prematurity**

Premature children are vulnerable to developing certain adverse health conditions in infancy such as intraventricular haemorrhage, bronchopulmonary dysplasia, necrotizing enterocolitis, retinopathy and sepsis, placing them at higher risk of delayed development (Thomaidis et al., 2014). Respiratory distress syndrome is common amongst extremely premature infants due to their lack of surfactant and their immature lungs (Schiariti et al., 2008; Levene et al., 2008; Nosarti et al., 2010; Potharst et al., 2013).

Gastrointestinal immaturities lead to poor food absorption and digestion, leading to insufficient weight gaining and growth (Bjornvad et al., 2005; Neu, 2007). Apnoea or bradycardia due to prematurity is related to gestational age, which result in most of these infants ending on ventilation (Scott et al., 2011).

#### **2.3.1.2 Birthweight:**

Birth weight appears to be a main role player with regards to negative outcomes in a child's physical and emotional development. The lower the birth weight and gestation, the larger the impact on a child's future development. According to literature, low birth weight infants (at term or premature) have ongoing health concerns and higher rates of morbidity at preschool and school age. These infants are more prone to behavioural problems, namely attention deficit disorder, conduct disorders and hyperactivity and these conditions are more prevalent with decreasing birth weight (Wolke and Meyer, 1999; Levene et al., 2008).

LBW and ELBW premature children demonstrate a higher incidence of neurological impairment, which can manifest itself as either cerebral palsy, epilepsy, deafness, blindness, mental retardation, and language, behavioural and learning disorders (Wolke and Meyer, 1999; Levene et al., 2008; Nosarti et al., 2010).

#### **2.3.1.3 APGAR scores**

The Apgar scoring system was intended as an evaluative measure of a newborn's condition at birth and of the need for immediate attention, therefore an infant's Apgar scores (at 1 min and after 5 min ) is taken after birth (Montgomery, 2000). Research from Lupton et al (2009) have cautioned

against prediction of later neurological dysfunction based solely on low Apgar's scores at 5 minutes, although there is a higher risk for death or cerebral palsy with low Apgar scores (Laptook et al., 2009). Nosarti and colleagues have demonstrated that, the lower the 5 min Apgar scores, the greater the risk of long term impairments (Nosarti et al., 2010). Nosarti et al. (2010) also found that low Apgar scores at 5 minutes combined with preterm birth, can be a predictor of behaviour problems in children and depressive disorder in adulthood (Nosarti et al., 2010).

#### **2.3.1.4 Events in NICU:**

The developing brain is very sensitive to extrinsic factors and therefore neonatal medicine and interventions need to protect the central nervous system in order to minimise future ailments (Sweeney, Heriza, Blanchard, 2009; Spittle and Orton, 2014). Premature infants are exposed to various extrinsic influences originating from their experiences within the Neonatal Intensive Care Unit (NICU) such as excessive noise, light exposure and human handling. These factors are reported to negatively affect the attainment of developmental milestones during early life (Levene et al., 2008; Schepers et al., 2011) and might lead to more serious problems later in life.

#### **2.3.2 Post discharge care and home environment:**

The post discharge environment continues to affect a child's development and are associated with negative developmental outcomes such as neurological disorders, increased risks of chronic conditions, physical problems and social problems (Levene et al., 2008; Schepers et al., 2011).

Premature children from low socioeconomic circumstances are at risk for poorer developmental outcomes, increased risk of chronic conditions, physical problems and social problems (Levene et al., 2008) which in turn are linked to an increased need for special education and healthcare services as they tend to be more frequently hospitalised (Hack et al., 1994; Schepers et al., 2011; Potijk et al., 2013).

The post-discharge environment such as family income, life style, support systems, education and access to early interventions will also be a major contributor to long term outcomes of these infants (Hack et al., 1994; Schepers et al., 2011; Potijk et al., 2013). The association between poor motor performance and these risk factors is not well understood and possible trends and similarities should be identified to help address specific problems.

In summary, research suggests that 25-50 % of premature infants show some sort of developmental problem such as motor delays, poor emotional regulation and inadequate language skills (Wolke and Meyer, 1999; Luciana, 2003). Various researchers agree and confirm that children born extremely prematurely are known to have an increased risk of developing neurodevelopmental disabilities

affecting multiple domains of functioning (Wolke and Meyer, 1999; Luciana, 2003). However, research mention that LP infants are the fastest growing group of neonates, with unanticipated complications later in life such as behaviour problems and specific age-related-acquired motor functions (Loftin et al., 2010). Changes in drug therapy (surfactant and antenatal steroids), mechanical ventilation and general NICU health care have contributed to more favourable outcomes (Ballot et al., 2012).

## **2.4 Prematurity and Motor Performance**

Deficits in coordination, balance, gross and fine motor control and visomotor integration, are more prevalent in premature children, and these children are reported to present with motor difficulties proportionate to their gestational age (Wolke and Meyer, 1999; Levene et al., 2008). Severe disability seen in this group is often directly linked to disrupted early brain development and structural damage to the developing brain (De Regnier, 2008; Mansson and Stjernqist, 2014).

A meta-analysis on cognitive and behavioural problems in school-aged children who were born preterm show that the immature brains of premature infants have the ability to modify their own structure and function (called plasticity) following changes within the body or the external environment (Bhutta et al., 2002; Luciana, 2003). Therefore, it can be assumed that early identification of impairments related to prematurity, and subsequent intervention may support the child in reaching developmental outcomes by school-ready age (Sweeney et al., 2009; Spittle and Orton, 2014).

Motor deficits are graded according to the different levels of impairments (Spittle and Orton, 2014). The degree of motor deficits in children born prematurely can range from mild (such as DCD, mild CP with no cognitive impairments) to severe (such as the more serious variations of CP) (Spittle and Orton, 2014). Motor impairments without CP include problems with coordination, balance, fine and gross motor control and visual motor integration (Williams, Lee, Anderson, 2010; Edwards et al., 2011; Spittle and Orton, 2014). These children struggle with basic everyday activities, such as dressing and tying shoelaces. (Goyen and Lui, 2009; Edwards et al., 2011).

Literature indicates that MP infants in the foundation school phase, show a higher incidence of developmental, behavioural and social problems which leads to the need for further educational assistance (Kerstjens et al., 2012; Cserjesi et al. 2012; Kerstjens et al., 2013). Moderate or late premature children are considered by health care professionals as being at low risk for morbidity. However, these (MP) children also present with milder problems affecting either multiple or singular domains of function, such as motor, language and cognitive development (Chyi et al., 2008; Van Baar et al., 2009; Van Baar et al., 2013).

The LP group shows the highest survival numbers of all premature infants (Van Baar et al., 2009; Van Baar et al., 2013). Literature indicates that they have more difficulties, problems and impairments than were expected or anticipated. This is because it was mistakenly assumed that this group was physiological and metabolically as mature as full term infants (Chyi et al., 2008; Van Baar et al., 2009; Loftin et al., 2010; Van Baar et al., 2013).

Advances in medicine over the past 2 decades have changed care for EP infants (Glass et al., 2015). The improved neonatal care, for example pharmacological interventions, improved nursing care and improved equipment, resulted in an increased amount of premature survivors that reach school age, therefore their health and educational needs should be properly identified and accordingly addressed, especially in extremely premature children who have a higher risk for poor neurodevelopmental and health outcomes (Withfield et al., 1997; Hack et al., 2011).

Despite advances, literature is still concerned about the high risks of developing neurological impairments when they are 4 to 8 years old, therefore extremely premature and ELBW infants carry their risks till they in the foundation school phase (Hack et al., 2011; Glass et al., 2015). Recent studies showed, that EP and ELBW infants had math and language delays, compared with those born at full term. Medical conditions, such as respiratory and immune system deficits are also more evident in these infants (Kessenich, 2003; Hack et al., 2011; Glass et al., 2015).

Therefore, long-term follow up to detect and address developmental, learning, behavioural and social problems, is imperative for EP and ELBW infants as it will minimize impairments and delays.

#### **2.4.1 Prematurity and Developmental Coordination Disorder:**

Developmental Coordination Disorder (DCD) is a problem affecting both full term and preterm children, although literature shows a higher incidence of DCD in preterm children (Zwicker and Harris, 2008; Zwicker, Yoon, MacKay, Petrie-Thomas, Rogers, Synnes, 2013). DCD affects a child's HRQoL and school achievements and should therefore not be ignored as its impact will continue into adulthood (Zwicker and Harris, 2008; Zwicker et al., 2013).

According to a study conducted by Ferguson et al. (2013), the DCD numbers in South Africa are assumed to be higher, due to socioeconomic factors (Ferguson et al., 2013). Although neonatal risk factors are contributing factors to most problems in preterm infants, Zwicker et al. (2013) could not identify a relationship between these and DCD (Zwicker et al., 2013). In contrast, Larsen et al. (2013) and Zhu et al. (2012) agree that intrauterine growth restriction (IUGR, thus low birth weight) and delayed walking attainment are also strong risk factors for DCD (Zhu, Olsen, Olesen, 2012; Larsen,



Mortensen, Martinussen, Anderson, 2013). Other research found an increased risk of DCD in postnatal steroid exposure and low birth weight infants (Edwards et al., 2011; Zhu et al., 2012; Larsen et al., 2013; Zwicker et al., 2013). There is also global consensus about the higher incidence of DCD in the male gender population (Zhu et al., 2012; Zwicker et al., 2013; Seelaender, Fidler, Hadders-Algra, 2013; Larsen et al., 2013), therefore making gender an important risk factor.

## **2.5 Prematurity and Emotional/Behavioural problems**

Various researchers agree and confirm that children born extremely prematurely are known to have an increased risk of developing neurodevelopmental disabilities affecting multiple domains of functioning. In other words, behavioural, cognitive and physical development is affected, such as in the case of cerebral palsy (Guerra et al., 2013; Spittle and Orton, 2014). Severe disability seen in this group is often directly linked to disrupted early brain development and structural damage to the developing brain (De Regnier, 2008; Mansson and Stjernqist, 2014).

Moderately born premature infants in the foundation school phase, show a higher incidence of lower intelligence and poorer neuropsychological functioning such as behavioural and social problems with not much differences in motor skill compared to full term children (Kerstjens et al., 2013; Cserjesi et al., 2012). Research from Kerstjens et al. (2012) indicated hypoglycaemia to be an indicator for later developmental delays in the foundation school phase (Kerstjens et al., 2012).

## **2.6 Prematurity and Health Related Quality of Life**

Health related quality of life (HRQOL) is a multidimensional measure that focuses on measuring the health of a person, as well as the outcome of certain medical treatments and possible intervention programmes (Donohue, 2002). Donohue (2002) defines HRQOL as “the physical, psychological, and social domains of health, which can be influenced by an individual’s experiences and perception”. The measurement of HRQoL assists researchers in determining the load of morbidity, evaluating outcomes and establishing the financial implications of interventions (Drotar, 2004). It is especially valuable in the paediatric setting to help parents and caregivers understand a child’s experience of his/her own health and how it compares to that of his/her peers (Boss, Kinsman, Donohue, 2012), thus determining a better comprehension of specific HRQoL issues.

In a review of health related quality of life (HRQoL) of premature children, Zwicker and colleague (2008) conclude that the effects of preterm birth/very low birth weight on health-related quality of life appear to decrease over time. They speculate that this could be due to individual changes and different definitions of HRQoL (Zwicker and Harris, 2008). However, premature children of preschool age (3-6 years) are reported to perform more poorly than their peers in physical, emotional, and/or social functioning (Zwicker and Harris, 2008).

Interestingly, some research shows controversial findings and opposing results of HRQoL when looking at VLBW/ELBW children. Hack et al. (2007) could not find a significant difference in HRQoL between the VLBW group and the control group. Thus, the researchers reasoned that children seem to have better adapting skills at an older age, whereas younger children have a lower HRQoL. This is because they struggle more with health-related and physical problems which prevents them from rendering an acceptable score (Saigal et al., 2006; Hack et al., 2007).

Additionally, formerly premature school-aged children are reported to have lower health utility scores compared to their peers. Similar results are also found in the case of adolescents. However, young adults reported a quality of life similar to normal birth weight peers (Hack et al., 2007; Zwicker and Harris, 2008).

## **2.7 Identification of functional problems at school age**

In order to monitor the long term impact of prematurity on motor control and HRQoL, valid, standardised measuring instruments need to be used in order to ensure that results are comparable, valid and reliable. Validated and reliable outcome measures are essential to ensure the internal validity of any descriptive study.

### **2.7.1 Assessment of Motor Performance**

The *Movement Assessment Battery for Children, second edition (MABC-2)* is one of the most commonly utilised measures of motor performance in school age children (age 3-16 years). However, there are other measures with different age ranges that can be used to determine motor performance in infants until the coming of age of a child. Examples of such measures are the Bruininks-Oseretsky of motor proficiency (BOT 2; ages 4-21 years), the Bayley Scales of Infant Development (1-42 months) and Peabody developmental motor scale II (PDMS-2; birth – 5 years) – all can be used to determine a child's motor and mental skills, as well as behaviour at different ages (Bayley, 1993; Folio and Fewell, 2000; Provost et al. , 2004; Bruininks, 2005; Wang, Liao, Hsieh, 2006; Deitz, Kartin, Kopp, 2007).

The MABC-2 contains eight tasks, divided into three sub-sections: manual dexterity, ball skills, and balance. The total test scores are converted to standard score equivalents and percentile scores using age-norm tables. Poor performance is represented by low standard scores. A total standard score (TSS) of 9-19 places a child in the **green** zone (no motor difficulty), a score of 6-8 falls in the **orange/amber** zone (at risk of having motor difficulty) and standard score between 1-5 places a child in the **red** zone (definite motor problems and an indication of DCD).

Venetsanou et al. (2011) report good inter-rater reliability and test-retest reliability (Venetsanou, Kambas, Ellinoudis, Fatouros, Giannakidou, Kourtessis, 2011). Henderson et al. (2007) also indicate an ICC value of 0.95 with a SEM value of 1.34 to be reliable (Henderson, Sugden, Barnett, 2007). Although there are no norms for the MABC-2 in South Africa it has been used in numerous South African studies which focus on motor development and developmental coordination disorder (DCD) (Ferguson et al., 2013). Although the MABC is a reliable measure for identification of mild to moderate motor impairment in young children, it can only be administered by trained professionals and still show a substantial standard error of measurement (Van Waelvelde et al., 2007; Smits-Engelsman et al., 2008; Cools et al., 2009).

### **2.7.2 Assessment of Motor Function**

The *MABC-checklist* consists of a series of age and school grade referenced questions related to a child's movement and motor function in a classroom setting, thus relying on the help of teachers or parents to determine if some of the children have motor coordination problems (Henderson et al., 2007).

The items in the checklist are divided into two sections, each of which considers a child's performance in progressively more complex situations. Section A is about movement in a static and/or predictable environment and section B is about movement in a dynamic and/or unpredictable movement (Henderson et al., 2007).

In addition, the behaviour section of the checklist, section C is about non-motor factors that might affect movement. Percentile scores categorise the child's performance via the 'traffic light' (same as the MABC) system that indicates whether further action is needed (**green** = no movement difficulty, **orange/amber** = at risk for motor difficulty, **red** = significant motor difficulty). High scores on the MABC-checklist represent poor performance (Henderson et al., 2007).

Junaid et al. (2000) conducted a study on teachers' use of the MABC-checklist to identify children with motor coordination difficulties. The results however did not support the independent use of the checklist alone for the identification of motor coordination problems in children, especially by teachers as it did not correlate with the sensitivity of the MABC-2 motor test (Junaid et al., 2000). A study from Schoemaker et al. (2012) investigated the validity and reliability of the MABC-checklist against the Developmental Coordination Disorder Questionnaire (DCDQ'07), they found that the checklist was a better predictor for motor function than the DCDQ, although the sensitivity was low, the checklist was acceptable for the standards of validity and reliability (Schoemaker et al., 2012). Contradicting Schoemaker et al. (2012) was Capistrano et al. (2015) where they looked at the validation of the MABC-

2 and the MABC-checklist according to the DCDQ, they found that the MABC-checklist showed lower levels of validity with the DCDQ (Capistrano et al., 2015).

### **2.7.3 Assessment of Behaviour and Emotional status**

The strengths and difficulties questionnaire (SDQ) is used to assess behavioural and emotional problems in children ages 3-16. Other questionnaires such as the Children's Behaviour Questionnaire (CBQ), Child and Adolescent Survey of Experiences (CASE-C/P) provide assessment of temperament and stressful life experiences from parents and teachers perspectives (Rothbart et al., 2001; Putman and Rothbart, 2006; Allen and Rapee, 2009; Allen, Rapee, Sandberg, 2012). The SDQ has shown satisfactory reliability and validity when used in research. It is a free of charge questionnaire and are therefore frequently used by clinicians and researchers.

The strengths and difficulties questionnaire (SDQ) consists of 25 items that are divided into 5 sections, namely 1) emotional symptoms (5 items), 2) conduct problems (5 items), 3) hyperactivity/attention deficit (5 items), 4) peer relationship problems (5 items) and 5) prosocial behaviour (5 items). Identical or nearly identical parent and teacher versions are available.

The 25 items in the SDQ (appendix V and VI) comprise 5 scales of 5 items each. For each of the 5 scales the score can range from 0 to 10 if all items were completed. Total difficulties score is generated by summing scores from all the scales except the prosocial scale. The resultant score ranges from 0 to 40, and is counted as missing if one of the 4 component scores is missing. Scores are converted into categories for the total difficulties Score. Scores of 0-13 indicate normal, 14-16 suggest borderline problems and 17-40 indicates abnormal behaviour.

The SDQ impact supplement asks if the parent/teacher thinks the child has a problem with emotions, concentration behaviour or getting along with people. If the answer is yes, the parent/teacher is asked about its impact on a child's home life, friendships, classroom learning and leisure activities (Goodman, 2001). When respondents have answered 'no' to the first question on the impact supplement (i.e. when they do not perceive themselves as having any emotional or behavioural difficulties), they are not asked to complete the questions on resultant distress or impairment; the impact score is automatically scored zero in these circumstances. The same categorisation, as used for the total difficulties score is used in the impact supplement.

Goodman (2001) reports an internal consistency of 0.73, with a test-retest reliability of 0.62, and cross-informant correlation of 0.34. He also confirms the proportion of true negatives around 95 %, with the sensitivities and positive predictive values around 35 %.

#### **2.7.4 Assessment of Health Related Quality of Life (HRQoL)**

There are several HRQoL instruments that have been developed for children, including the Child Health Utility 9D reference, the PedsQoL, the Kidscreen (Ravens-Sieberger et al., 2010; Varni et al., 2011; Stevens, 2012). However, as the EQ-5D-Y has been validated in South Africa and is available in Afrikaans and other South African languages, it was chosen to determine HRQoL in children (Wille et al., 2010).

The EQ-5D-Y is a self-completed questionnaire, designed for children and adolescents concerning HRQoL. It consists of five dimensions (mobility, looking after myself, doing usual activities, having pain or discomfort, feeling worried, sad or unhappy) each of which have one of three responses (no, some and a lot of problems) (The EuroQol Group, 1990). The EQ-5D-Y also has a visual analogue scale (VAS) to measure a child's health in the present moment (The EuroQol Group, 1990). The EQ-5D-Y questionnaire was tested by Ravens-Siebere et al. (2010) for feasibility, reliability, and validity, in a South African environment. The results revealed that 91% and 100% of the respondents provided valid scorings. Percentages of agreement in test-retest reliability ranged between 69.8 and 99.7% in the EQ-5D-Y dimensions. Kappa coefficients were up to 0.67, which make it acceptable (Ravens-Sieberger et al., 2010).

The EQ-5D-Y- is the self-administered youth version for children and adolescents aged 7-12 years. At present, this version is available in 9 different languages, making it a suitable choice for this research, as it was available in the mother tongue of the participating children. The questionnaire consists of a descriptive system and a Visual Analogue scale (EQ VAS).

The descriptive system comprises 5 dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression). Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. This decision results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health state. It should be noted that the numerals 1-5 have no arithmetic properties and should not be used as a cardinal score.

The EQ VAS records the respondent's self-rated health on a 20 cm vertical, visual analogue scale with endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. This information can be used as a quantitative measure of health as judged by the individual respondents. The EQ-5D-5L asks respondents to simply 'mark an X on the scale to indicate how your health is TODAY' and then to 'write the number you marked on the scale in the box below'.

## **2.8 Conclusion:**

A logical consequence of the increased survival rate of premature infants is the growing number of premature children in mainstream education. These children are at risk of developing poor social, behavioural and adaptive skills, which may all have an impact on health related quality of life (HRQoL) (Msall and Park, 2008).

Despite the numerous research studies focusing on the impact of prematurity on social, behavioural, cognitive and adaptive skills of this population, we identified a gap in literature with regards to the functional performance of this population at school age. Although many studies have focused on the neurological and cognitive outcomes of ELBW in infant years, there is still a shortage of information about the effect and implication on these children during their school careers (Neubauer, Voss, Kattner, 2007). In particular, very little research has been conducted in South Africa on this group. This shows the importance of further follow-up research, and design and implementation of appropriate support services to minimise possible short- and long-term problems and complications.

Since the premature infant is faced with various health challenges in his/her life compared to full term infants, there is an increased awareness of the HRQoL of these infants (Levene et al., 2008; Nosarti et al., 2010). Therefore, this research intends to compare the HRQoL of learners in Grade R, 1 and 2 to that of FT children. In addition we will demonstrate the different interpretations of their strengths and difficulties amongst the child, the parents and teachers. Increased knowledge of the various limitations of premature children helps to provide new insight for interventions to prevent impairments or to reduce these late disabilities in very premature children are needed.

In the next chapter we will describe the scientific process followed in answering the research question of differences in motor performance, HRQoL and emotional- behaviour profile of children (in grades R, 1 and 2; age range: 5-8) who were born prematurely and at full term. Comparison in performance of children born at different stages of prematurity (late, moderate and extremely premature) and to establish the extent to which certain neonatal and maternal factors were associated with performance outcomes at primary school age.

### 3 METHODOLOGY

#### 3.1 Research design

A descriptive, cross-sectional study design was used.

#### 3.2 Sample

A sample of convenience, consisting of children in the primary foundation phase, (i.e. grades R, 1 and 2) was used to select children that met the inclusion criteria for the PREM group.

One full term (FT) child of the same age, gender and grade was then randomly chosen from the school admission records to match each child in the PREM group.

#### 3.3 Research setting

The study was conducted in 15 mainstream schools, randomly selected from a pool of 115 schools located within in a 100 km radius of Bloemfontein. The schools used in this study represented an array of socioeconomic quintiles<sup>1</sup> (See Table 2). Mainstream schools were selected in order to determine the impact of challenges faced in these schools where resources are limited (compared to special need schools).

*Table 2: Description of Schools in research setting*

<i>Type of School</i>	<i>School</i>	<i>Size (learners)</i>	<i>Socioeconomic status</i>
Quintile 1: no fee schools	A	270	Low and middle
	B	510	Low and middle
	C	175	Low and middle
Quintile 2: no fee schools	D	470	Low
	E	960	Low
	F	550	Low
Quintile 3: no fee schools	H	560	Low and middle
	I	210	Middle
Quintile 4: fee paying schools	J	780	Middle and high
Quintile 5: fee paying schools	K	1500	Middle and high
	L	940	Middle and high
	M	660	Middle and high
	N	560	Middle and high
	O	1	High
Private: fee paying schools	G	700	High

<sup>1</sup>According to the Department of Education in South Africa, all public schools are categorised into five groups, called quintiles, largely for the purposes of allocating financial resources. Quintile 1 represents the poorest and quintile 5 the least poor public school. **Quintiles 1-3 are no-fee schools**, whereas **quintile 4 and 5 are fee-paying schools**.

### **3.4 Inclusion criteria**

School admission records were used to identify PREM children. All children with a gestational age < 37 weeks, residing in the Bloemfontein area (or 100 km radius), who were currently enrolled in Grade R, 1, or 2 at the identified mainstream schools (n=15) and who were age 5-9 years at the time, were eligible for inclusion.

All children with a gestational age  $\geq 37$  weeks, residing in the Bloemfontein area (or 100 km radius), who were currently enrolled in Grade R, 1, or 2 at a mainstream school, aged 5-9 years were eligible for inclusion in the FT group.

### **3.5 Exclusion criteria**

Since we were interested in children attending mainstream schools, they should not have cognitive hampering, but minimal motor deficits (no more than GMFCS level I, II) were allowed and a child should still be able to participate in MABC testing. Therefore, children with moderate to severe physical disability although normal cognition (GMFCS level III, IV and V) or acute injury or illness at the time of recruitment and testing were excluded. Two children (PREM) were confined to wheelchairs (GMFCS level IV) and were thus excluded. As the MABC measures physical ability, children who were unable to walk independently were excluded. Some of the schools were full-service schools (see definition), an initiative from The Department of Basic Education to create an education system for all needs, resulting in children with special needs that attend mainstream schools. Only children who could participate in the motor function part of this study, were selected.

### **3.6 Sample size calculation**

As regression analysis required at least 10 participants per predictive variable and it was anticipated that about 10 variables would be entered, at least 100 participants were needed. However, it was unknown how many of those participants were going to agree to participate and how many of them attended Grade R, 1 or 2. As a result, it was decided that all children from each school that fit the criteria should be potential participants.



### **3.7 Measurement instruments**

The following instruments were used in the study.

#### **3.7.1 Self-designed Medical and Demographic Questionnaire**

A self-designed questionnaire (Appendix I) was used to record demographic and medical information from parents, medical records, school admission records and clinic cards. We included a checklist of variables reported to be linked to poor outcomes, such as length of hospital stay, length on ventilation, surgery, and steroidal medication (Hack et al., 1994; Zwicker et al., 2013).

#### **3.7.2 Movement Assessment Battery for Children, 2nd Edition (MABC-2) and Checklist**

The MABC-2 (Age Band 1 and 2) (Appendix II and III), and the MABC-2 Checklist (Henderson et al., 2007) (Appendix IV) were used to assess the motor performance and function of the participants. These tests are considered valid and reliable measures of motor performance and functioning. A full description of these assessments can be found in the Literature review (Chapter 2).

Total standard scores and percentile scores were used to classify children's performance into three categories: A total standard score (TSS) of 9-19 suggested no motor difficulty, a score (TSS) of 6-8 was taken as being at risk of having motor difficulty and standard score between 1-5 was definitive of motor problems. High scores on the MABC-checklist represent poor performance.

#### **3.7.3 Strengths and Difficulties Questionnaire (SDQ) - Parent and Teacher Version**

The Strengths and difficulties questionnaire (SDQ) was used to assess behavioural and emotional problems and was completed by parents and teachers (Appendix V and VI). A full description of the SDQ can be found in the Literature review (Chapter 2).

The Total Difficulties Score and Impact scores were recorded for each child. Each of these scores were then categorised as either: Normal, Borderline or Abnormal in accordance with the SDQ scoring instructions.

#### **3.7.4 EQ-5D-Y Questionnaire**

The self-report EQ-5D-Y was used to determine HRQoL in the participants (Appendix VII). The English and Afrikaans versions were used. The VAS and domain scores were recorded for each child. A high score on the VAS indicates better HRQoL. A full description of these assessments can be found in the Literature review (Chapter 2). As this research age group was 5-8 years, the questions was

carefully explained and read out loud for the 5-6 year olds-the research assistant made sure they understood what each question meant.

### **3.8 Testers/Researchers**

A qualified occupational therapist was employed as a research assistant to assist with recruitment and transfer information from school admission documents, parents' personal files and clinic records to the Self-designed questionnaire. She was not involved in the testing of participants. She was trained in the ethical considerations for this proposal and was asked to sign a confidentiality agreement.

The researcher was assisted by a group of testers (two qualified, trained occupational therapists, with extensive experience in working with children) who received training in the administration of all the instruments to ensure reliability. These testers were assigned to help the parents and teachers with the questionnaires (SDQ-parent and teacher, MABC-checklist). All questionnaires were reviewed in training to avoid any misinterpretation from the tester and the parents/teachers.

The MABC-2 was administered by the researcher.

### **3.9 Procedure**

The following steps were taken to conduct the study.

#### **3.9.1 Ethical Approval**

Ethical approval was obtained from the Human Research Ethics Committee, Faculty of Health Sciences of the University of Cape Town (HREC reference number 694/2014).

#### **3.9.2 Permissions:**

The Department of Education of the Free State were contacted, and a list of schools in the Bloemfontein area and 100 km surroundings were requested. Permission to access school records (databases) and conduct the study in the Bloemfontein schools was obtained.

Permission were also requested for each school headmaster and its learners to participate in this research study. Each headmaster of the different schools involved was contacted and permission obtained.

#### **3.9.3 Informed consent and Assent**

Participation to this study was completely voluntary and did not incur any costs to the participant. Informed consent and assent were obtained from all parents and children. Assent was obtained at schools after the families had been visited at their homes. The study was explained to the children in an

age appropriate manner and thereafter they were given time to decide whether they wanted to participate (if they did not, then they were not enrolled, even if their parents had consented). Whether the child was aware of his premature status or not was discussed with parents before gaining assent from the child.

#### **3.9.4 Pilot study**

A pilot study was done to determine the feasibility of the research study in terms of time (i.e. time to locate the various participants, time to complete questionnaires, competency of testers, cooperation from children and parents and time management between the different measurement instruments), availability of participants, funding and infrastructure. The pilot study served as a method to detect flaws in the protocol as well as the problems with administration of different instruments. This made it possible for the researcher to correct possible flaws and limitations before commencement of the actual study. It also gave an indication of possible results.

A pilot study consisting of twenty participants (10 premature children, 10 full term children) and their parents/guardians was conducted. These participants were identified from the same cohort/database. This took place according to the same procedure as planned for the study.

The pilot study brought valuable insights into the process of the research study. Due to the use of a standardised measure instrument and questionnaires, the duration of the motor assessments took longer than expected as the researcher did not have previous experience (apart from her training) on the MABC-2 and at one school, an interpreter had to help explain the instructions of the MABC-2 and questions raised from the questionnaires. Two of the schools did not have a gym area anymore, as it was used as class –or storage room; testing had to be done in an open classroom or space provided by the school headmaster. Teachers and parents understood the questionnaires, and the trained testers were well prepared for any indistinctness or questions that came forward.

The data from the pilot study was excluded from the final analysis. The way forward for data collection was based on the same procedure as the pilot study, time management were better distribute amongst the researcher and testers in terms of administrating the MABC-2, explanation of instructions and answering of questions. The pilot study gave a clear indication on the time used per child, parent and teacher. It also provided an estimated timeframe for completion of all participants.

#### **3.9.5 Recruitment**

A list of all schools in the Bloemfontein region (and 100 km surrounds) was requested from the Department of Education. Schools were categorised in terms of the different quintiles. The names of all the schools located in each of the five school quintiles were then placed in five hats. Thus, 15 schools

(8 from no fees quintiles and 7 from fee paying quintiles) were randomly selected from the names-in-a-hat method.

The research assistant accessed the school admission records database to identify premature children in grade R, 1 and 2. This list was stratified into gestation age, gender, age and address. The research assistant then randomly selected (names in a hat method) one full term children from the school admission records to match each child with a premature birth history from the same class and same age and gender. Contact details of each child and their parent were extracted for recruitment.

### **3.9.6 Enrolment**

After the sample was identified, phone numbers and addresses were verified and each child's parents/guardians were contacted by the research assistant. Telephonically, the research assistant confirmed whether or not children were born prematurely or full term, and if they were still residing in the prescribed study area.

Parents were then informed of the intended study and were asked to provide information regarding whether any exclusion criteria applied. Two children were confined to wheelchairs (GMFCS level IV) and were thus excluded.

After they agreed telephonically to take part in the study, written information of the study was sent to them (either by mail, email or fax) and a formal meeting was arranged with them at their homes. At this meeting, an information sheet was handed to each participant and their parents/guardians as well as the appropriate consent forms. The details of the study were discussed and questions regarding the study were answered. Thereafter, parents/guardians were asked to sign the consent forms.

Children, their parents/guardians, teachers and testers (qualified occupational therapists) were given a time schedule for when and where testing would take place.

Grade R, 1 and 2 teachers from each school were asked to attend a meeting where the study was explained to them. Informed consent was obtained from all teachers.

### **3.9.7 Data collection**

The research assistants extracted medical data and other relevant data from the school admission forms. If some data were missing, parents' were requested to submit personal medical files on their children or clinic cards. She transferred all the data to the Self- designed Questionnaire. She also assisted in the signing of consent/assent forms. The research assistant had interviews with parents to fill-in missing

data if there was information not clear or left out from the children's school admission forms or clinic cards. The parents were also asked to bring all extra documents on a child along on the day of testing.

The list of names of all the children enrolled in the study- without the gestational age and the schools they attended, were then given to the researcher who travelled with the testers to the different schools to test all the children involved in the study (April – November 2015). All testing was done in the afternoon, after school, to limit possible questions/interest from other children and parents and the impact of missing class.

The MABC-2 were administered on an individual basis (by the researcher) to each child in the school's gym area or any other suitable open classroom if the school did not have a gym area. The researcher was blinded to the gestational age of each child.

One tester (tester 1) administered the EQ-5D-Y to each child either before or after they had completed the MABC-2 test with the researcher. Confidentiality and privacy were taken into account as all testing was done in private rooms. Both teachers and parents were assisted by another tester (tester 2) assigned to assist teachers with the SDQ-teacher questionnaire and MABC-checklist in one classroom, while parents completed the SDQ-parent questionnaire in a separate classroom. All testers were blinded to gestational age.

After data collection, the researcher personally engaged with the parents by giving advice or referring to a multidisciplinary team member where children scored poorly.

### **3.10 Data management:**

All consent forms, assessment forms and the records of treatment were kept in individual folders for every child. Folders were numbered to maintain anonymity and stored in a locked cupboard in the primary researcher's office. The data were entered into Excel spread sheets weekly and hard copies were moved to the principal investigator's office and stored in a locked cupboard.

Consent forms were numbered and filed along with the other forms of information collected for each learner. Demographic questionnaires were coded and entered along with the participants' reference number. The information from each assessment score sheet was also entered electronically on an excel spreadsheet.

All electronic data was password protected. The coded data were stored on an external hard drive with password protection. Data will be stored for at least five years.

### **3.11 Statistical analysis**

All analyses were conducted using STATISTICA 10 and SAS® Version 9.4. The default significance level was set at 0.05.

The data of full term and premature children were summarized using descriptive statistics (number of available data (n), mean, and standard deviation, minimum, median and maximum).

Descriptive data (mean, mode, medians, and tables) were used to summarise the central tendency of motor function, burden of care and HRQoL of the two groups. Frequency distribution in frequency tables were also used to show different response categories of variables.

The t-test and the Mann Whitney test were used to compare the two groups with normally distributed data. Correlations between the premature and full term participants as well as the strength of the linear relationship were done by the Spearman rho and Kappa coefficient. The Kruskal Wallis ANOVA was used to determine the difference in motor performance between groups.

### **3.12 Ethical Considerations**

The study conformed to the Helsinki Declaration (World Medical Association declaration of Helsinki, 2013). After the data collection period, parents received written reports of their child's performance; no one else had access to the results. It was at the discretion of the parents whether they would share the results with a child's teacher. In the cases of caregivers, the correct legal channels will followed to share a child's results with the correct legal guardian.

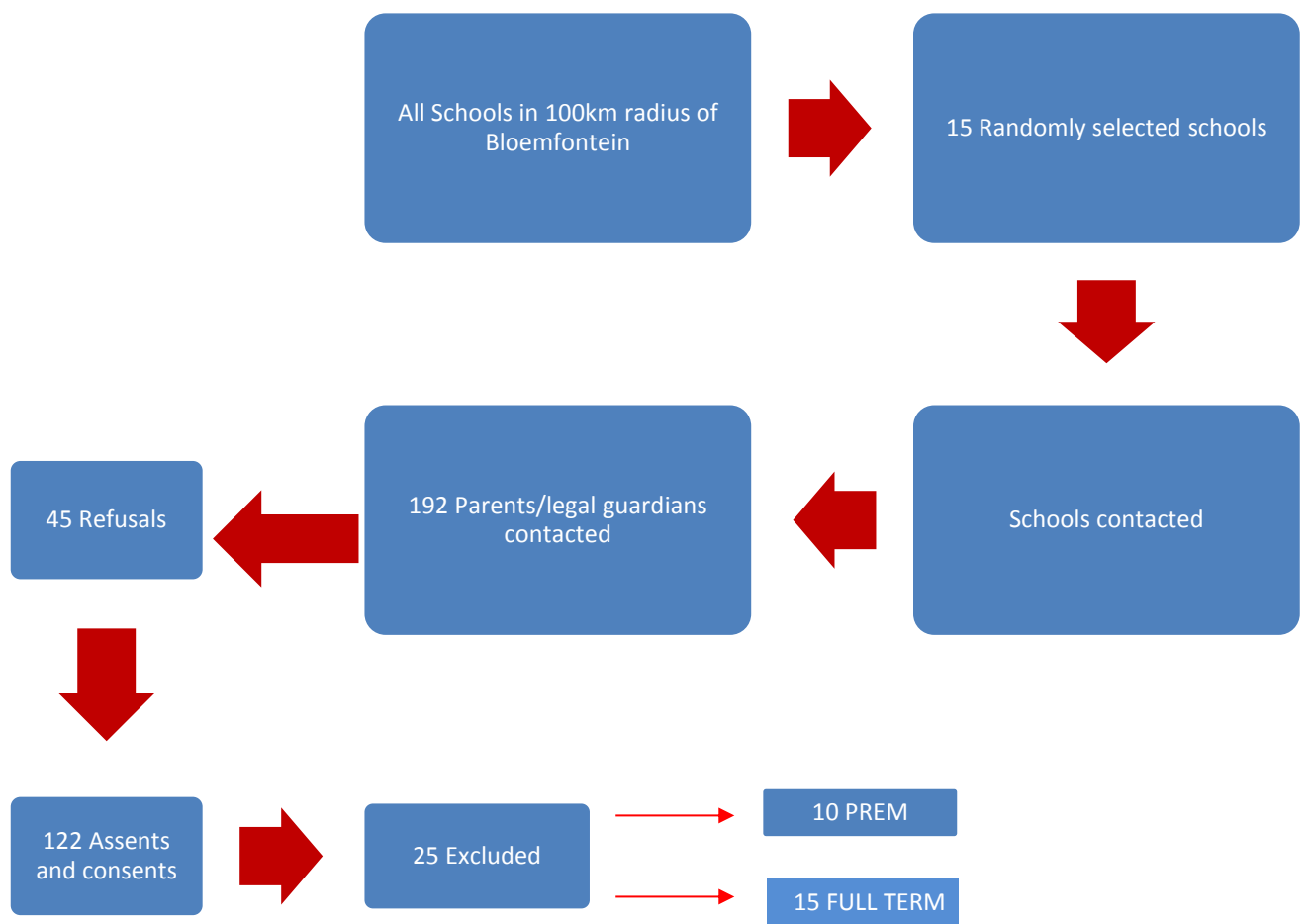
Parents of children with motor problems were given a referral letter which contained information on their child's motor performance. This letter could be taken to any therapist (physiotherapist, occupational therapist) either in private practice or in public service. A contact list of registered therapists was provided to all parents whose children had been assessed as part of the study; however, the researcher and her testers' names were omitted from the list to ensure that there was no conflict of interest and to adhere to ethical professionalism. Similarly, parents were informed of possible services available in public healthcare.

## **4 RESULTS**

A comparison of the demographic characteristics and medical histories of the four groups will first be described. Next we examine the association between group membership and maternal risk factors. This will then be followed by a comparison of the groups in terms of motor performance, health related quality of life and emotional-behaviour profile.

### **4.1 Final sample**

The final sample was comprised of 122 participants. They were identified as follows (see figure 1). From the 192 parents and legal guardians contacted, there were 45 children and parents who did not want to participate in the research study (147 were willing to participate). 122 children and their parents gave assent. The 25 that were excluded did not fit the inclusion criteria or were sick on the day of testing; they were excluded were from both the PREM and FULL term groups. 10 children from the PREM group were excluded (5 children were absent from school on the day of testing, 2 children were confined to wheelchairs and 3 children did not want to participate anymore although they gave assent before). 15 FULL term children were excluded (8 children were absent on the day of testing, 4 children were sick on the day of testing and 3 children were no longer learners from the school on the day of testing). The children that were GMFCS I and II, were highly functional children (in terms of BOTOX management, and were participating in sports).



***Figure 1: Progression of research process***



## 4.2 Characteristics of the sample

122 children participated in this study (59 males, 63 females) and the median age of the total sample was 7 years (IQR: 6 to 7 years). All children spoke either English or Afrikaans.

The inclusion criteria resulted in the formation of two groups (*Full Term*: n = 61 and *PREM*: n = 61) of similar age (p = 0.610), gender (p = 0.856) and class grade (p = 0.976).

**Table 3: Comparison of Full term (n = 61) and Preterm (n = 61) infants – child age (years) and gender**

Variable		FT N=61	PREM N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (3 groups)
<b>Median Child age years (IQR)</b>		6.0 (6-7)	7.0 (6-7)	U = 1760 Z = -0.51 p = 0.610	6.0 (5-7)	7.0 (6-7)	7.0 (6-8)	Chi = 13.45 df = 8 p = 0.10
<b>Gender</b>	Males	30	29	Chi = 0.03 p = 0.856	13	11	5	Chi = 1.26 df = 2 p = 0.53
	Females	31	32		10	16	6	
<b>Grade N (%)</b>	R	20 (32.8)	20 (32.8)	Chi = 0.05 p = 0.976	10	7	3	Chi = 5.39 df = 4 p = 0.25
	1	22 (36.1)	23 (37.7)		10	10	3	
	2	19 (31.1)	18 (29.5)		3	10	5	

As expected, groups were significantly different in terms of mean gestational age (FT: 38 weeks vs PREM: 33 weeks, p < 0.001) and significantly different in terms of birth weight (FT: 3150 g, PREM: 2201 g, p < 0.001).

**Table 4: Comparison of Full term (n = 61) and Preterm (n = 61) infants – gestational age (weeks) and birth weight**

Variable	FT N=61	PREM N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (3 groups)
<b>Median gestational age weeks (IQR)</b>	38 (38-39)	33 (30-35)	U = 0.00. z = 9.52 p < 0.0001	35 (34-36)	31 (30-33)	27 (27-28)	H (2, N= 61) =51.86 p < 0.0001
<b>Median birth weight-kg (IQR)</b>	3150 (2890-3330)	2201 (1750-2650)	U = 475.5, z = 7.10, p < 0.0001	2500 (2270-2982)	2360 (1750-2640)	1090 (960-1480)	H ( 2, N= 61) =23.13 p < 0.0001

The PREM group were categorised into different levels of prematurity. There were 23 children who were late premature (34-36 weeks), 27 who were classified as moderate to very premature (29-33 weeks) and 11 who were extremely ( $\leq 28$  weeks) premature. The differences between the subgroups of premature infants followed the same pattern as the comparison between FT and PREM groups (i.e. no differences in mean age at testing, gender and grade distribution; significant differences between gestational age and birth weight).

Regarding the socioeconomic (SES) profiles of the two groups, we found that groups were not different in terms of maternal education level ( $p=0.15$ ) or school quintiles ( $p=0.07$ ). Similarly, within the PREM group, there were no significant differences.

**Table 5: Comparison of four groups (FT, LP, MP, and EP) in terms of SES profiles**

Variable		FT N=61	PREM N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (3 groups)
Education level of mother	Some high school	1	6	Chi = 3.79 df = 2 $p = 0.15$	3	3	0	Chi = 2.58 df = 4 $p = 0.630$
	Grade 12	16	15		4	7	4	
	Tertiary qualification	44	40		16	17	7	
Socioeconomic status (school quintile)	Quintile 1 + 2	19	25	Chi = 5.22, df = 2 $p = 0.07$	9	10	6	Chi = 5.86 df = 4 $p = 0.210$
	Quintile 3+ 4	6	12		3	5	4	
	Quintile 5	36	24		11	12	1	

### 4.3 Maternal/Antenatal factors associated with PRETERM

Maternal age at child's birth was significantly different between FT and PREM groups ( $p < 0.001$ ) with the mothers in the PREM group being significantly older (mean age: 31.9 years SD = 5.2, range: 17-43 years) than the mothers in the FT group (mean age: 29.1 years SD = 3.5, range: 22-37 years).

Children in the PREM group were 0.69 times more likely to have been delivered by Caesarean Section. All but two PREM group (both in moderate to very prem category) were born via C/section ( $p < 0.0001$ ).

**Table 6: Maternal risk factors – maternal age, type of delivery, type of pregnancy**

Variable		FT N=61	PREM N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (4 groups)
Mean Maternal age (SD)	Years	29.0 (3.5)	31.9 (5.2)	$t = 3.61$ , df = 120, $p < 0.001$	33.4 (4.4)	31.6 (6.2)	29.7 (4.7)	$F = 6.37$ , df = 118, $p < 0.0001$
Type of delivery (%)	NVD	20 (32.8)	2 (3.3)	Chi = 17.96, df = 1, $p < 0.001$ OR = 14.39 (3.18 - 64.95)	0	2	0	Chi = 18.52, df = 3, $p = 0.0003$
	C/S	41 (67.2)	59 (96.7%)		23	25	11	
Type of pregnancy	Singleton	55	53	Chi = 0.32, df = 1, $p = 0.57$ OR = 0.72 (0.23 - 2.23)	20	25	8	Chi = 3.36, df = 3, $p = 0.34$
	Multiple	6	8		3	2	3	

NVD = Normal vertex delivery, C/S Caesarean Section. OR = Odds ratio

Only two mothers, one in the PREM and one in the FT group, reported having smoked during pregnancy. More mothers in the PREM group were having hypertension ( $p = 0.04$ ). There were no significant differences between FT and PREM groups with regards to the number of mothers reporting to have diabetes ( $p = 0.51$ ) or asthma ( $p = 0.43$ ). Within the PREM group however, the moderately premature group had more mothers with Asthma ( $p = 0.04$ ). Three mothers in the PREM group had had previous premature births whereas none of the mothers in the FT group had delivered a premature child, however this difference between groups was not significant ( $p = 0.07$ ).

**Table 7: Maternal risk factors** – diabetes, hypertension, asthma, previous premature births

Variable		FT N=61	PREM N=61	Statistics (2 groups)	LP N=23	MP N=27	EP N=11	Statistics (4 groups)
<b>Diabetes</b>	Yes	6	4	Chi = 4.36 df = 1 $p = 0.51$ OR = 1.55 (0.42 - 5.81)	2	1	1	Chi = 0.64 df = 2 $p = 0.72$
	No	55	57		21	26	10	
<b>Hypertension</b>	Yes	7	16	Chi = 4.34 df = 1 $p = 0.04$ OR = 0.36 (0.14 - 0.96)	6	6	4	Chi = 5.36 df = 3, $p = 0.15$
	No	54	45		17	21	7	
<b>Asthma</b>	Yes	7	10	Chi = 0.62 df = 1 $p = 0.43$ OR = 0.66 (0.23 - 1.87)	1	8	1	Chi = 76.31 df = 2 $p = 0.04$
	No	54	51		22	19	10	
<b>Previous premature births</b>	Yes	0	3	Chi = 3.07 df = 1, $p = 0.07$	2	0	1	Chi = 2.50 df = 2 $p = 0.28$
	No	61	58		21	27	10	

*NVD = Normal vertex delivery, C/S Caesarean Section. OR = Odds ratio*

#### 4.4 Neonatal Differences between groups

As expected, the APGAR scores were significantly different between FT and PREM groups at 5 min ( $p < 0.001$ ). On examination of PREM subgroups, the Late PREM group (mean rank: 38.87) had significantly higher APGAR scores than the extreme PREM group (mean rank: 16.04,  $p < 0.0013$ ). No differences were found between moderate and Late ( $p = 0.27$ ) and between moderate and extreme ( $p = 0.07$ ).

**Table 8: Association of Apgar (5 min) in the four groups (FT, LP, MP and EP)**

Variable	FT N=61	PRE M N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (3 groups)
Median Apgar 5 min (IQR)	10 (9-10)	8 (8-9)	U = 1040, z = -4.19, p < 0.0001	9 (8-10)	8 (8-9)	8 (7-8)	H (2, N = 61) = 13.69 p = 0.0011

The neonatal complications are listed in Table 9. Apart from a single case of respiratory distress in a FT child, no FT children had neonatal complications.

Within the PREM group, respiratory distress was the most common neonatal complication (62.3 %), followed by treatment with post-natal steroids (40.9 %), apnoea (36.1 %) and patent ductus arteriosus (PDA) (34.4 %). The extreme PREM group presented with most problems in all areas. Most significantly, in respiratory distress (p = 0.02), and PDA (p = 0.01).

**Table 9: Neonatal complications**

	FT N = 61	PREM N = 61	Late PREM N = 23	Moderate PREM N = 27	Extreme PREM N = 11	Statistics (3 groups)
Respiratory distress (n)	1	38	10 (43.5 %)	18 (66.7 %)	10 (90.9 %)	Chi = 7.52, df = 2, <b>p = 0.02</b>
Septicaemia (n)	0	5	1 (4.3 %)	2 (7.4 %)	2 (18.2 %)	Chi = 1.93 df = 2 p = 0.38
Post-natal steroids (n)	0	25	6 (26.1 %)	12 (44.4 %)	7 (63.6 %)	Chi = 4.577 df = 2 p = 0.10
Apnoea (n)	0	22	8 (34.8 %)	6 (22.2 %)	8 (72.7 %)	Chi = 8.67 df = 2 <b>p = 0.01</b>
PDA (n)	0	21	5 (21.7 %)	8 (29.6 %)	8 (72.7 %)	Chi = 9.06 df = 2 <b>p = 0.01</b>
Grade 1 or 2 Haemorrhaging (n)	0	14	2 (8.7 %)	7 (25.9 %)	5 (45.5 %)	Chi = 5.9 df = 2, <b>p = 0.05</b>
Gr. 3, 4 Haemorrhaging (n)	0	2	0	1	1	Chi = 1.96, df = 2, p = 0.37

Table 10 shows that 60.6% of those in the PREM group were hospitalised subsequent to the neonatal period ( $p < 0.0001$ ).

**Table 10: Interventions received in the four groups (FT, LP, MP and EP)**

Variable		FT N=61	PREM N=61	Statistics (2 groups)	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics (4 groups)
Lifetime Hospitalisation	Yes	6 (9.8 %)	37 (60.6 %)	Chi = 34.5, df = 1 <b><math>p &lt; 0.0001</math></b> OR 0.07 (0.03 - 0.19)	11 (47.8 %)	16 (59.3 %)	10 (90.9 %)	Chi = 40.6 df = 3 <b><math>p &lt; 0.0001</math></b>
	No	55	24		12	11	1	

## 4.5 Motor performance (MABC-2)

There were significant differences between the PREM and FT groups on the MABC-2. The FT group scored higher than the PREM group on the overall MABC TSS ( $p = 0.025$ ). The differences were in the areas of Manual dexterity ( $p = 0.012$ ) and Balance ( $p = 0.049$ ) (Table 11). Within the PREM group, there were no significant differences in overall TSS between groups ( $p = 0.095$ ). On examination of component scores, the moderate prem group were significantly better in terms of balance scores than the late prem group ( $p = 0.037$ ).

**Table 11: Motor performance in the two groups (FT and PREM) as determined by the MABC-2**

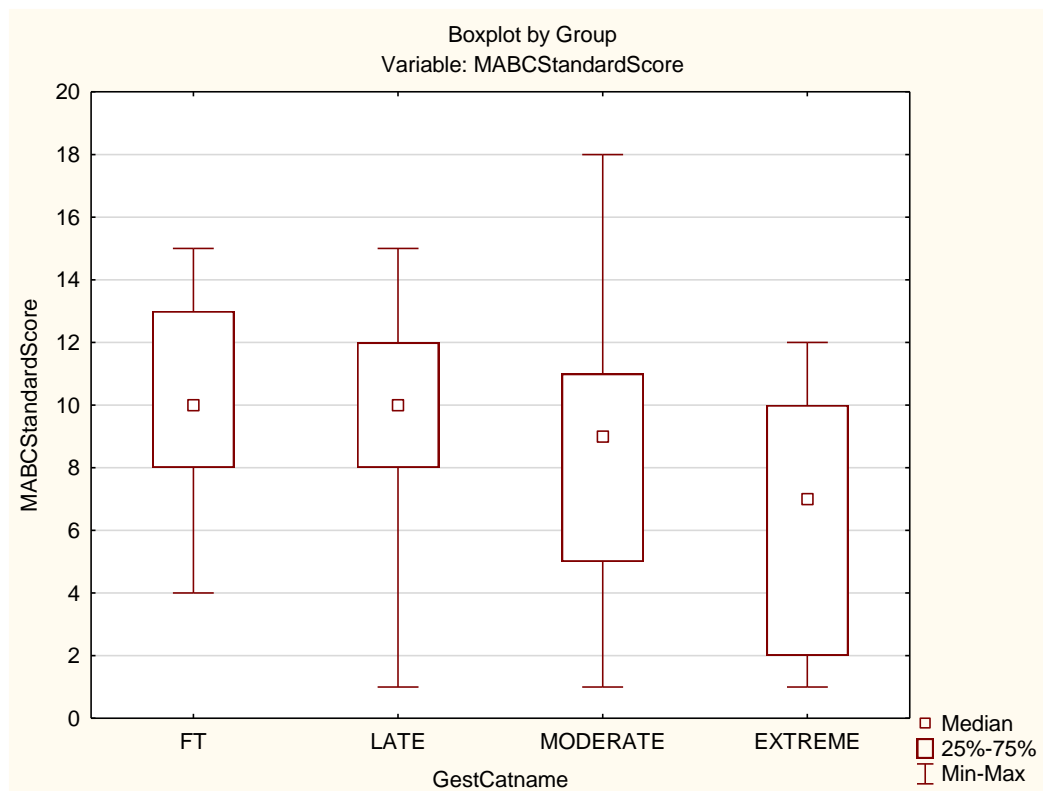
MABC-2 Component	Median (IQR) FT	Median (IQR) PREM	Statistics (2 groups)	Mean Rank Late PREM N=23	Mean Rank Moderate PREM N=27	Mean Rank Extreme PREM N=11	Statistics groups
Manual Dexterity Component Standard Score	8 (6-10)	7 (5-9)	U = 1374, z = 2.51, p = 0.012	8 (7-10)	6 (4-7)	5 (4-8)	H ( 2, N= 61) =7.90 <b><math>p = 0.019</math></b>
Aiming and Catching Component Standard Score	11 (9-12)	10 (9-13)	U = 1715, z = 0.75, p = 0.454	10 (8-13)	11 (9-13)	9 (8-12)	H ( 2, N= 61) =1.44 p = 0.49
Balance Component Standard Score	11 (10-14)	10 (8-14)	U = 1479, z = 1.97, p = 0.049	9 (8-14)	11 (8-15)	9 (4-10)	H ( 2, N= 61) =6.39 <b><math>p = 0.04</math></b>
MABC Total Standard Score (TSS)	10 (8-13)	9 (6-11)	U = 1425, z = 2.24, p = 0.025	10 (8-12)	9 (5-11)	7 (2-10)	H ( 2, N= 61) =4.70 p = 0.095

Evidently, poorer motor performance was associated with prematurity ( $p = 0.023$ ), with 23 children in the PREM group (37.7 %) categorised as red or amber, compared to 10 (16.4 %) in the FT group on the MABC-2 classification. Within the PREM group, poorer motor performance was not associated with degree of prematurity ( $p = 0.191$ ).

**Table 12: Categorical motor performance on the MABC-2**

Traffic light (motor difficulty)	Full term group	Premature group	Statistics 2 groups	Late PREM N=23	Moderate PREM N=27	Extreme PREM N=11	Statistics 3 groups
Red	4	14	Chi-Square =14.66, $p = 0.023$	3	7	4	Chi-Square =6.10, $p = 0.191$
Amber	6	8		2	3	3	
Green	51	39		18	17	4	

22 premature children scored in the red and amber zone, which accounts for about a one third of the premature group and 10 full term children also had poor motor performance.



**Figure 2: MABC standard scores across the different groups (FT, LP, MP and EP)**

Although a trend was observed in that the scores decreased with level of prematurity, the confidence intervals were wide. Multiple comparison of Mean ranks indicated that the differences were between the extremely premature children and the FT children ( $p = 0.018$ ). Differences between other groups were not significant.

**Table 13: Multiple comparison of Mean ranks (MABC Standard Scores) across levels of prematurity (p-values)**

Level of prematurity	FT	LATE	MODERATE	EXTREME
Mean Rank	68.64	63.26	54.98	34.23
FT		1.0	0.57	0.02
Late	1.0		1.0	0.15
Moderate	0.57	1.0		0.61
Extreme	0.02	0.15	0.60	

## 4.6 Motor Function (MABC Checklist)

The PREM group scored higher than the FT group on all items on the MABC Checklist, suggesting poorer performance.

**Table 14: Motor performance in the two groups (FT and PREM) as determined by the MABC-checklist**

MABC Checklist*	Median (IQR) FT	Median (IQR) PREM	U	Z adjusted	p-value
Movement in static environment	2 (1-5)	5 (2-9)	1291	-2.93	0.003
Movement in dynamic environment	5 (3-7)	10 (5-20)	1039	-4.22	< .001
Total Motor Score	7 (4-11)	17 (9-26)	1017	-4.32	< .001

\*Note that a higher score denotes a poorer performance

**Table 15: Categorised motor performance on the MABC-Checklist**

Traffic light (motor difficulty)	Full term group	Premature group	Row Total
Red	7	26	33
Amber	5	7	12
Green	49	28	77

*Chi-Square = 17.0, p < .001*

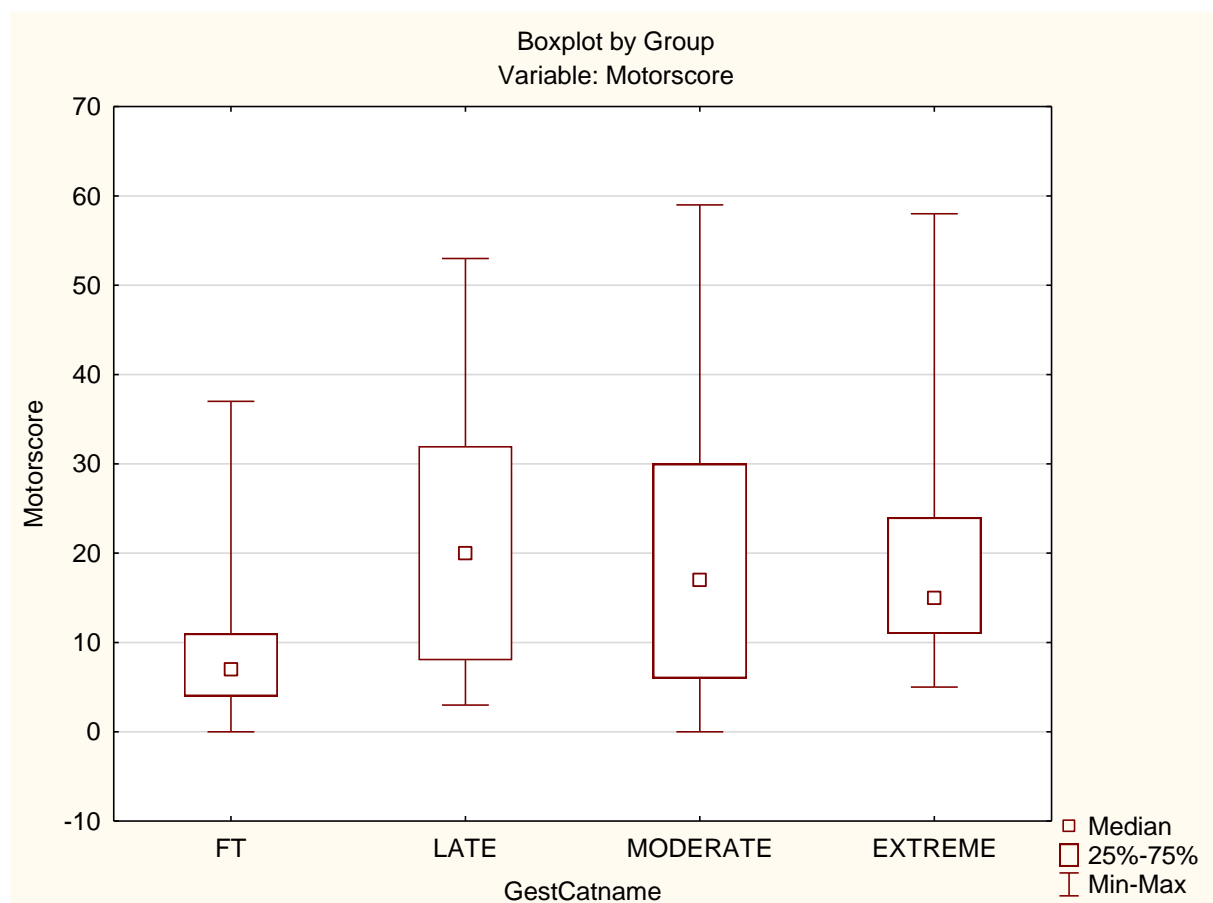
When analysing motor scores from the MABC-checklist (completed by teachers), the degree of motor difficulty is evident in the premature group (n = 33 |red and amber).

There was a significant difference in the scores of FT children and children who were late, moderate to very and extremely premature  $H(3, N = 122) = 19.0, p = .0003$ . The largest difference was between the FT and Late PREM groups ( $p = 0.003$ ) and moderate ( $p = 0.013$ ). There was trend for difference

between the FT and extreme group ( $p = 0.061$ ). It would appear that the three PREM groups were not significantly different from each other.

**Table 16: Multiple comparison of Mean ranks (MABC-checklist Motor Scores) across levels of prematurity (p-values)**

Level of prematurity	FT	LATE	MODERATE	EXTREME
Mean Rank	47.66	77.57	72.59	77.41
FT		0.003	0.014	0.06
Late	0.003		1.0	1.0
Moderate	0.014	1.0		1.0
Extreme	0.06	1.0	1.0	

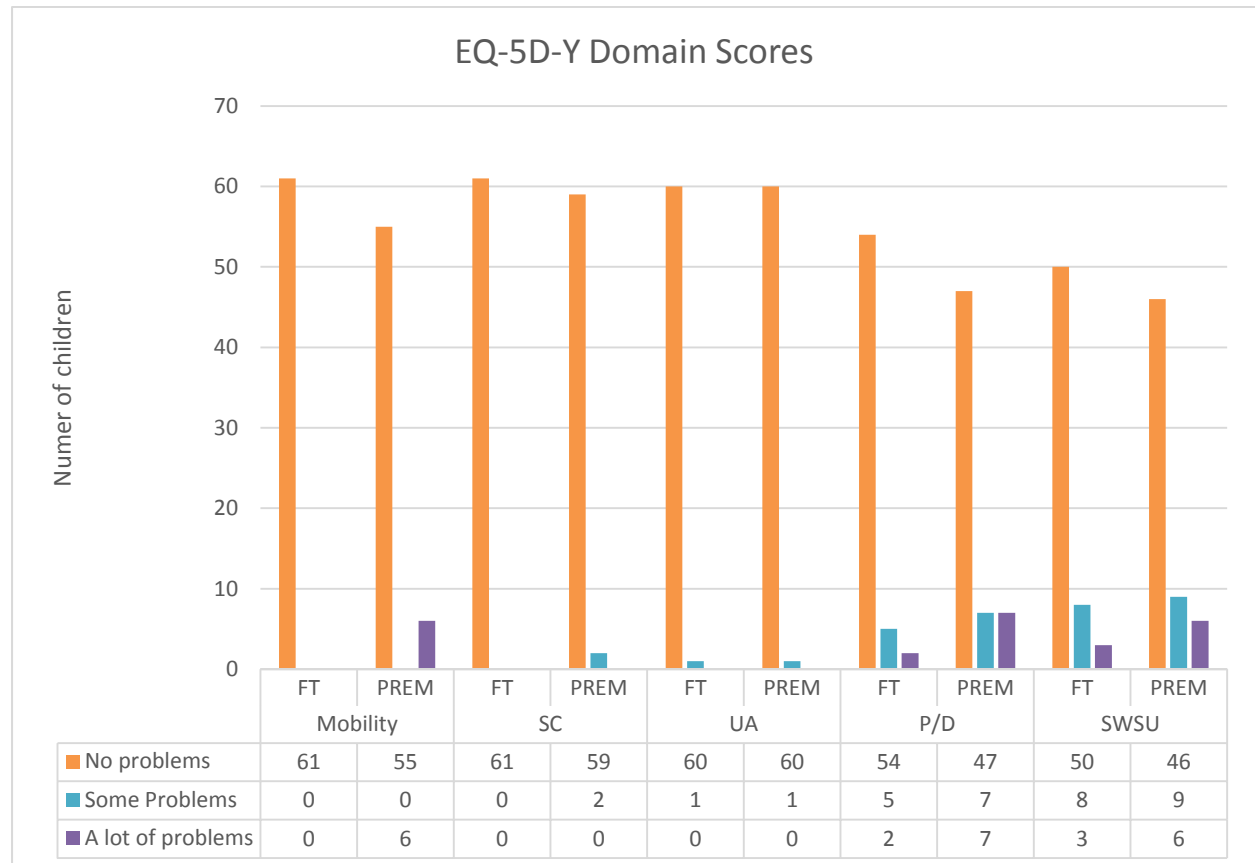


**Figure 3: MABC-checklist Total Motor scores across the different groups (FT, LP, MP and EP)**



## 4.7 HRQoL

Few children in either group reported problems in the Mobility, Self-care or Usual Activity domains (figure 4 below). In both FT and PREM groups, more children had problems with the Pain/Discomfort (P/D) and Worried/Sad/Unhappy (SWSU) domains and there was no association found between group and any domain apart from Mobility (Chi-Sq = 6.3,  $p = 0.012$ ).



**Figure 4: Responses to the EQ-5D-Y domains**

We found a significant difference in the VAS scores on the EQ-5D-Y with the PREM group children scoring 24 points lower than the FT group. The Mann Whitney U test showed the ranking was significantly different ( $U = 1578$ ,  $z = -2.7$ ,  $p = .007$ ) between FT (mean rank: 66.13) and PREM group (mean rank = 56.86). A significant difference in VAS scores between prem groups was also found [ $H(3, N = 122) = 9.108514$ ,  $p = .0279$ ].

**Table 17: Comparison of the four groups on EQ-5-D-Y**

Variable	Level	FT (N=61)	LP (N=23)	MP (N=27)	EP (N=11)	Statistics (4 groups)
Mobility	1	61	22	25	8	Chi = 15.28, df = 3, p = 0.0016
	2	0	0	0	0	
	3	0	1	2	3	
Looking After Myself	1	61	23	26	10	Chi = 5.90, df = 3, p = 0.116
	2	0	0	1	1	
	3	0	0	0	0	
Usual Activities	1	60	23	27	10	Chi = 4.62, df = 3, p = 0.202
	2	1	0	0	1	
	3	0	0	0	0	
Pain or Discomfort	1	54	19	19	9	Chi = 8.57, df = 3, p = 0.199
	2	5	2	3	2	
	3	2	2	5	0	
Worried/Sad/ Unhappy	1	50	16	22	8	Chi = 6.44, df = 3, p = 0.375
	2	8	3	3	3	
	3	2	4	2	0	

Results from Looking after myself, Usual activities, Pain/discomfort and Worried/sad/unhappy did not provide any difference between the four groups. However, there were a clear difference in mobility ( $p = 0.0016$ ) between the different groups.

#### 4.8 Emotional-Behavioural Profile

Comparison of the total scores on the SDQ between the two groups according to the parents and teachers is presented in table 18. The Mann Whitney U test was used to compare the two groups.

**Table 18: Comparison of the Parental and Teachers' SDQ results between groups**

Variable	Parent					Teacher				
	Rank Sum FT	Rank Sum PREM	U	Adj Z	p-value	Rank Sum FT	Rank Sum PREM	U	Adj Z	p-value
<i>Total difficulties</i>	3683	3821	1792	-0.35	0.725	3409	4094	1518	-1.76	0.079
Emotional	3499	4004	1608	-1.31	0.189	3295	4208	1404	-2.37	0.018
Conduct	3570	3934	1679	-0.96	0.339	3570	3933	1679	-0.97	0.334
Hyperactivity	3444	4060	1553	-1.59	0.111	3425	4079	1534	-1.69	0.091
Behaviour towards peer	3819	3685	1794	0.35	0.728	3526	3977	1635	-1.18	0.239
Prosocial	4125	3379	1488	1.96	0.050	4277	3226	1335	2.74	0.006
<i>Total Impairments</i>	3722	3782	1831	-0.33	0.739	3207	4296	1316	-3.25	0.001
Home	3596	3908	1705	-1.49	0.137					
Friend	3781	3722	1831	0.24	0.814	3551	3953	1660	-1.49	0.137
Class	3708	3795	1817	-0.34	0.732	3456	4047	1565	-2.03	0.042
Leisure	3626	3878	1735	-1.35	0.177					

FT  $n = 61$ , PREM  $n = 61$

On examination of the impact of behaviour on class room function, teachers noted significant differences between the PREM and FT groups ( $p = 0.042$ ) whereas parents did not think there were differences ( $p = 0.732$ ). According to the parents, there was a trend for FT and PREM groups to be significantly different in terms of prosocial behaviour scores ( $p = 0.050$ ). Teachers reported differences between FT and PREM groups in terms of emotional scores ( $p = 0.018$ ) and prosocial behaviour scores ( $p = 0.006$ ). In addition teachers reported differences in total impairments ( $p = 0.001$ ) whereas parents did not ( $p = 0.739$ ).

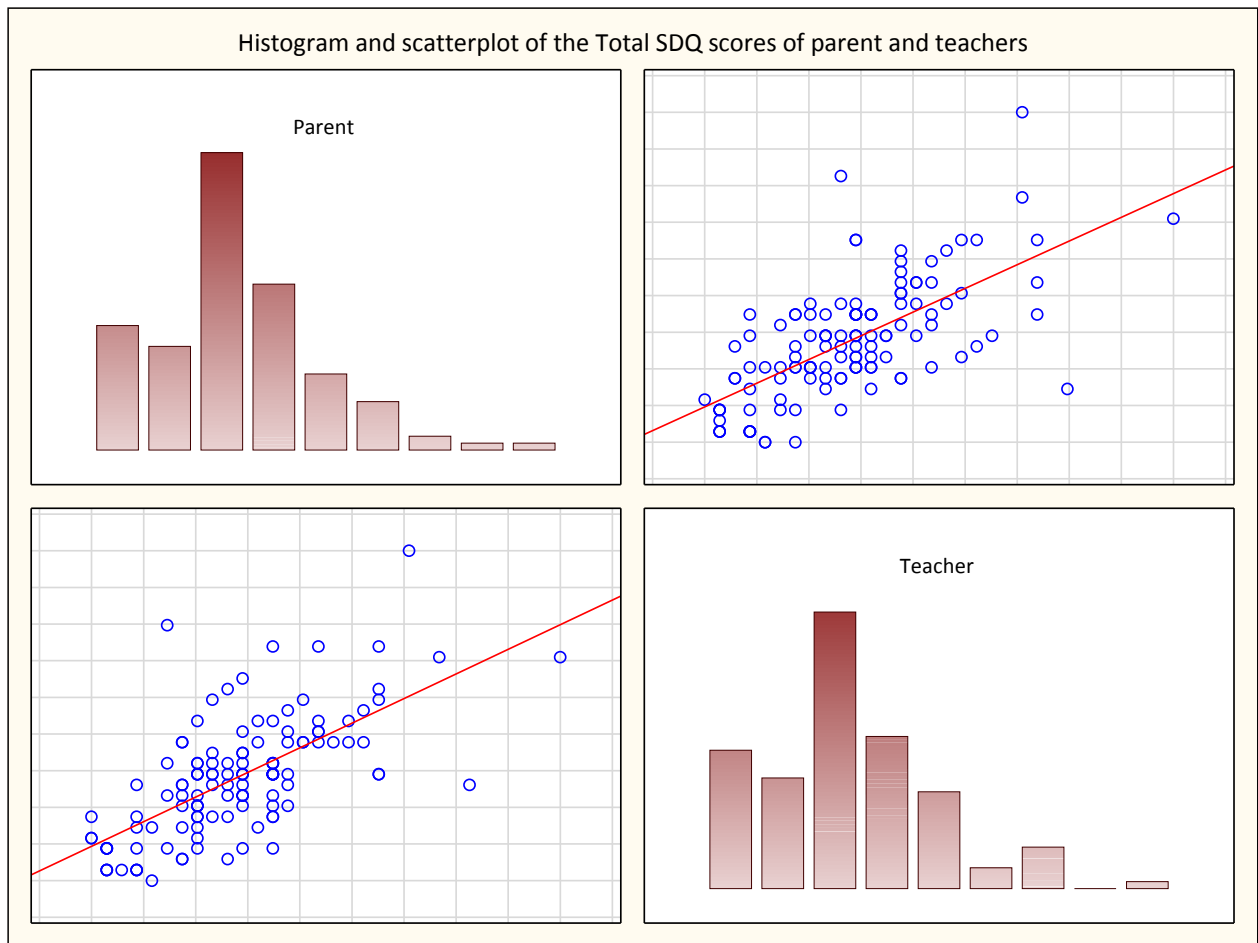
One-way ANOVA did not reveal any differences in the total scores across the levels of prematurity in either responses of the parents ( $F = .408$ ,  $p = .748$ ) or the teachers ( $f = 1.270$ ,  $p = .288$ ).

**Table 19: Comparison of the  $p$  values between *parents* and *teachers* in the different categories**

<b>Behavioural problem</b>	<b><i>Parents/caregivers</i> <math>P &lt;</math></b>	<b><i>Teachers</i> <math>P &lt;</math></b>
Hyperactivity	0.0039	0.0015
Conduct	0.3644	0.3393
Peer	0.7878	0.0547
Emotional	0.0409	0.0021
Prosocial	0.5943	0.1255

#### **4.8.1 Agreement between Teachers and Parents**

The correlation between the parental and teachers' total scores (Figure 5) was highly significant ( $\rho = .66$ ,  $p < .001$ ). The correlation of the total scores was further examined using the Kappa test which showed fair to substantial agreement in all domains apart from Hyperactivity and Peer problems and in the PREM group in the Pro-social domain (Table 20).



**Figure 5: Scatterplot of the total SDQ scores of the parents and the teachers**

**Table 20: Kappa scores representing agreement between parents and teachers**

Domain	Group	Kappa statistic	Strength of agreement between parents and teachers
<b>Total Difficulties</b>	FT	0.52	moderate
	PREM	0.42	moderate
<b>Emotional problems</b>	FT	0.24	fair
	PREM	0.25	fair
<b>Conduct problems</b>	FT	0.37	fair
	PREM	0.23	fair
<b>Hyperactivity problems</b>	FT	-0.062	no
	PREM	0.194	no
<b>Peer problems</b>	FT	0.09	no
	PREM	0.04	no
<b>Prosocial problems</b>	FT	0.65	substantial
	PREM	0.2	slight

## 4.9 Summary of results

The two groups were equivalent in terms of demographic factors (age, gender, and grade) as per the inclusion criteria. The PREM children had a lower birth weight and lower APGAR scores. Their mothers were older and they were more likely to be delivered by Caesarean section. The mothers of the PREM group were also more likely to have been hypertensive. The most common health conditions in the perinatal period were respiratory distress, need for post-natal steroid, apnoea and PDA. More children from the PREM group were hospitalised in the neonatal period.

The PREM children performed poorly in the Fine motor category, Manual dexterity and Dynamic Balance items. Their overall MABC test, standard and percentile scores were all significantly lower (lower = worse performance) and the MABC-Checklist significantly higher (higher = worse performance) than the FT group. Prematurity was associated with a lower categorised performance on both the MABC-2 and MABC Checklist.

The scores of the MABC-2 across the different levels of prematurity were significantly different between those with extreme prematurity and the FT groups. Differences between other groups on MABC-2 items were not significant. A similar result was seen on the MABC-checklist. The FT children scored significantly lower on the checklist items indicating better performance compared to children who were late and moderately premature.

There were few differences in the HRQoL of the two groups, with only problems in the Mobility domain being associated with PREM. The VAS was skewed with a small group in the PREM group reporting very low self-perceived HRQoL.

On the behaviour scale, the teachers reported the PREM group to have significantly lower score rankings in more items, including the Emotional, Total Impairments and behaviour in class items. Both parents and teachers identified differences in prosocial behaviour. However, there was no difference in the total scores between the PREM and FT groups by either group of respondents. There was also no difference between the scores of the different levels of prematurity by either group of respondents.

Parents/caregivers seemed to think that these difficulties (emotional, conduct, hyperactivity, peer and prosocial problems) did not have an impact on their children's friendships, classroom learning, and leisure activities or in their home life. However, teachers did feel that these difficulties have an influence on classroom learning.

## 5 DISCUSSION

The *primary* aim of the study was to compare the motor performance, HRQoL and emotional- behaviour profile of children (in grades R, 1 and 2; age range: 5-9 years) who were born prematurely and at full term. *Secondly*, to compare performance of children born at different stages of prematurity (late, moderate and extremely premature). *Finally*, to establish the extent to which certain neonatal and maternal factors (identified in the literature) were associated with performance outcomes at primary school age.

This discussion examines the generalisability of the results by looking at the characteristics of the sample. Thereafter the implication of the findings obtained from the MABC-2, MABC-checklist, the EQ-5D-Y and the SDQ (parent and teacher versions) will be discussed. The limitations of the study will be identified.

### 5.1 The sample

The sample included 61 full term children and 61 premature children, who were matched for age, gender and class. The age of participating children in this study ranged from 5-9 years and represented all cultural groups and various socioeconomic situations in Bloemfontein, South Africa. PREM and FT groups were recruited from the same schools, thus no differences were found in the SES of the two groups. Most mothers were highly educated (68.5% of total sample tertiary educated) which is surprisingly higher given the demographics of the Bloemfontein region which reports that 44.2 % of the population made matric or a have higher education (Statistics South Africa, 2011. <http://www.statssa.gov.za>).

The three subgroups of PREM children were identified as, Late Prem (n = 23), Moderate Prem (n = 27) and Extreme Prem (n = 11). In this research, the moderate premature group made up a bigger proportion of the premature group. This correlates with the PPIP report, where the same trend was noted for the South African premature population (Pattinson, Saving Babies [PPIP], 2012-2013). It appears that large proportions of late premature infants are entering mainstream education. This group were previously ignored due to incorrect assumptions of ‘them having minimal risks or problems’ (Morse et al., 2009).

#### 5.1.1 Maternal and Perinatal differences and impact

Maternal age at child’s birth was significantly different between FT and PREM groups ( $p < 0.001$ ) with the mothers in the PREM group being significantly older than the mothers in the FT group. This is in line with other findings suggesting that advanced maternal age predisposes women to adverse pregnancy outcomes such as preterm birth (Laopaiboon et al., 2014).

More mothers in the PREM group were having hypertension in contrast to the FT group. According to research, the combination of hypertension with advanced maternal age, is associated with a three-fold increased risk of delivery before 37 weeks' gestation (Bramham et al., 2014). In addition, hypertension during pregnancy may also lead to fetal growth retardation which will further alter an infant long term outcomes (Xiong et al., 2002; Laidus, 2011). Studies suggest that intra uterine growth retardation are at increased risk for motor and cognitive delay (Longo et al., 2013).

More children in the PREM group were delivered by Caesarean Section. This agree with research from Bhatta and Keriakos (2011) about increased caesarean section rates for preterm births and further indicated conflicting evidence regarding its benefits in increasing the survival rate for VLBW preterm births, thus suggesting that neonatal outcome does not depend on the mode of delivery (Bhatta and Keriakos, 2011).

However, more recent studies suggest that caesarean sections showed an increased risk in respiratory distress syndrome resulting in asthma later in life, also type 1 diabetes, overweight and obesity in adulthood (Werner et al., 2012; Darmasseelane et al., 2014),

#### **5.1.1.1 Birth weight**

While many small babies are premature, some full term babies might also be born with a low birth weight. In this research, 2 % of prem participants belonged to the < 1000 g (ELBW) group, 10 % were in the VLBW and 25 % were in the LBW group. This confirms the findings of Hack and colleagues (Hack, Klein, Taylor, 1995; Hack et al., 2000; Hack et al., 2002; Hack et al., 2009) about the increase in numbers of ELBW, VLBW and LBW infants despite their gestation.

Hack, Klein & Taylor (1995) tracked the long-term developmental outcomes of LBW infants and found that they suffer of mild problems (such as DCD and coordination problems) (Hack et al., 1995). However, further research on neurodevelopmental outcomes of ELBW infants indicated more neurodevelopmental abnormalities such as ADHD, autism and poor academic attainment than their LBW counterparts (Hack et al., 2000; Hack et al., 2009).

#### **5.1.1.2 Apgar scores**

Hegyi et al. (1998) indicated that low Apgar scores (< 3 at 1 min and < 6 at 5 min) was associated with birth weight, gestational age and mode of delivery (Hegyi et al., 1998). The full term group had a mean Apgar (at 5 min) score of 9.3, with the extremely premature group having a mean Apgar (at 5 min) score of 7.4; the extremely premature group showed a higher mean than what Hegyi et al. (1998) suggested to be critical.

Although there have been some controversy surrounding Apgar scoring in neonates, Lee and colleagues (2010), found the Apgar (5 min) score were still a significant indicator of neonatal mortality in all gestational ages from 24 – 36 weeks (Lee, Subeh, Gould, 2010). In addition, Gampel and Nomura (2014) report that low Apgar scores are predictors of later physical, neurological, cognitive and psychological abnormalities at age 4-8 years (Gampel and Nomura, 2014).

### 5.1.1.3 Health conditions

While a significant number of children in the premature group had health conditions in the neonatal period (i.e. respiratory distress, haemorrhaging, and the need for mechanical ventilation and steroids, only one Full term children had respiratory distress.

Of the 38 reported premature children that had **respiratory distress** in the neonatal period, more of them belonged to the moderate to very premature group. Respiratory problems related to MP include delayed neonatal transition to air breathing, surfactant deficiency and pulmonary hypertension (Hermansen and Lorah, 2007). Recent literature indicates LP and MP birth to be more common with more diagnostic and management challenges to medical personnel (Miall and Wallis, 2011; Kugelman and Colin, 2013). It is therefore an important risk factor for future development (Schariti et al., 2008).

16 PREM children suffered **haemorrhaging**. In this study, more children suffered grade 1, 2 haemorrhaging (2 in the LP, 7 MP and 5 EP group) than grade 3 and 4 (1 MP and 1 EP). Severely disabled school going children (GMFCS level III, IV and V) were excluded and this could have led to the finding that less children had grade 3 and 4 haemorrhaging. The moderate to very premature group showed the most grade 1, 2 haemorrhaging in the premature group. The brains of MP and LP infants is more vulnerable to haemorrhaging than full term infants due to the fact their brains are forced to carry out important phases of its development outside the womb, therefore these infants show more susceptibility to developmental impairments than FT infants (Neubauer et al., 2007; Hirvoenen et al., 2014). Some literature strongly indicated that more research should be done to investigate the specific effect of haemorrhaging in school age children, as clear and significant problems should be identified at a young age (Payne et al., 2013).

Antenatal administration of **corticosteroids** between 24 – 34 weeks' gestation reduces the risk of respiratory distress, especially when the risk of premature birth is high (Hermansen and Lorah, 2007). Crowther et al. (2006) further supported the repeat of antenatal corticosteroids as they found infants to have better outcomes to respiratory distress, lung disease and had a shorter time of mechanical ventilation however they could not indicated the safety of prenatal corticosteroids (Crowther et al., 2006). Neubauer et al. (2007) rule out the possibility of post-natal steroids being a risk factor. This



correlates with this research study as more premature children received anti-natal steroids, than post-natal steroids (Neubauer et al., 2007). However, Zwicker et al. (2013) identified post-natal steroids to be a risk factor for DCD (Zwicker et al., 2013). Furthermore, Neubauer et al., (2007) report more male children having received postnatal steroids. (Neubauer et al., 2007). This is contradicted by the study results as more females received post-natal and antenatal steroids. In addition, it was found that more males suffered of apnoea in the neonatal period than females.

29 PREM children from this research received **mechanical ventilation** (9 from the LP, 10 MP and 10 from the EP group). Thus, about half of the premature group in this research needed mechanical ventilation. Respiratory support is an important part of care in the NICU of premature infants, especially in extremely premature infants which have the highest risk of failure (Roumiantsev, 2013; Committee on fetus and newborn, 2014). Guerra et al. (2013) reported a possible correlation between mechanical ventilation and lower test scores since mechanical ventilation leads to barotrauma and resultant haemorrhaging in the lungs. These complications will increase hospital stay resulting in lower test scores (Guerra et al. 2013).

However mechanical ventilation in the NICU has also been evolving in an effort to improve the care of these delicate infants, literature suggest that short and long term effects of ventilation together with neurodevelopment should be further addressed as MP and EP infants still have substantial more risks for future problems (Brown and DiBlasi, 2011; Altman et al., 2011).

37 premature children reported more **frequent hospitalization** than their peers in the same grade, 11 from the LP group, 16 from the MP group and 10 from the EP group). These numbers correlates with literature, where the highest re-hospitalisation were in the LP and MP groups, as these groups contribute significantly to overall neonatal mortality rates (Escobar et al. , 2005; Brankovic et al., 2013). Stein et al. (2006) mention a lower number of impairments but with somewhat higher incidence of chronic medical conditions (such as lung conditions, infections, etc.), this is confirmed in the premature group of this research due to their regular hospitalisation (Stein, Siegel, Bauman, 2006).

## **5.2 Motor performance**

There is currently consensus that motor coordination problems are more prevalent in premature children, especially low birth weight, low gestation children (Zhu et al., 2012; Zwicker et al., 2013; Larsen et al., 2013; Seelaender et al. 2013; Spittle and Orton, 2014). The premature group, achieved lower scores in most of the motor test items of the MABC 2 and Checklist. Thus, the study corroborates the findings of key experts in the field which confirm that prematurity has an impact on a child's school performance and age appropriate motor function (Hutchinson et al., 2013).

The reasons for poor motor performance amongst children born prematurely relate to a host of factors. Firstly, it is believed that premature exposure to the extrauterine environment results in altered movement and sensory experiences on the developing musculoskeletal and central nervous systems such as smaller cortical surface area, lower grey and white matter volumes, and widespread microstructural abnormalities in preterm infants (Spittle and Orton, 2014). Further, the third trimester is known as a period of rapid brain development, thus preterm birth is thought to disrupt this process therefore premature infants are at elevated risk for problems with learning, communication, emotional regulation, and social bonding later in life (Spittle and Orton, 2014).

There are several biological factors that may influence motor development postnatally. These factors include insufficient growth (reduced weight, height and head circumference) and smaller muscle size (with less fast-twitch muscle fibres). Alterations in maturation of the brain may also influence motor development. Environmental influences such as parent-child interactions, expectations and experiences may also be influenced when a child is born prematurely.

Preterm infants at term age also exhibit different neurobehavioral and motor strategies compared to an infant born at term. They may exhibit a decreased flexor muscle tone and use more extended postures. They may also have monotonous spontaneous movements against a background of hypotonicity and may find it particularly difficult to perform antigravity movements (Spittle and Orton, 2014).

Literature suggests that moderately premature children have more motor function and coordination difficulties (Van Baar et al., 2009; Cserjesi et al., 2012; Perricone et al., 2013). Our findings reveal no difference between prematurity groups in this research, as the preterm children with more problems are attending special need schools. This is in contrast to Perricone et al. (2013) who suggests that when moderately premature birth occurs with low birth weight, these children have an increased risk for neurodevelopmental problems (Perricone, Morales, Anzalone, 2013). Our research is line with Guerra et al. (2013) who found that late premature children presented with equivalent scores on the Bayley III scales as moderately premature children.

Studies suggest that children born extremely preterm are at significant risk of persistent impairments in neurocognitive function and academic achievement. However, it appears this is not the case in this study concerning motor performance, as EP children from this research were no different in performance compared to MP and LP, although children with severe motor and cognitive problems were not part of the inclusion criteria for this research.

Due to the fact that moderately premature children make up a bigger proportion of the premature spectrum, there is a consensus that moderately premature children are more at risk for age-specific

motor and behaviour problems in the primary foundation phase (Kerstjens et al., 2013). These psychological problems are further confirmed by Perricone et al. (2013) where they also agreed that moderately premature children accompanied by low birth weight, tend to be more susceptible to attention, cognitive and self-regulation problems which might lead to ADHD in the long run. This only present itself when a child is school age (Perricone et al. 2013).

### **5.3 HRQoL**

There is a need to obtain more information to assess the burden of prematurity on the children themselves. As such, the HRQoL of children born preterm should be taken into account when planning interventions. However, there is limited research on former premature children and their quality of life among school-aged children (Vederhus et al., 2010; Payot and Barrington, 2011; Vederhus et al., 2015).

This study found that more children, in both groups had problems with the Pain/Discomfort (P/D) and Worried/Sad/Unhappy (SWSU) domains compared to the mobility, Self-Care and Usual activities domains. The main difference between FT and PREM groups was that the premature group reported more problems with mobility. In addition, significant difference in the VAS scores on the EQ-5D-Y were also found with the PREM group children scoring lower than the FT group. Evidently, the poor motor performance in premature children has a negative impact on this domain of HRQOL. This is in contrast to findings by Huhtala et al (2016) who reported that the preterm children did not report lower HRQoL than FT children if they had survived without significant morbidities (Huhtala et al., 2016).

Preterm birth and its associated with various problems related to mobility, everyday functional activities of daily living as well social, emotional and behavioural problems. However, the relationship between preterm birth and HRQoL is complicated. Despite higher rates of activity limitations, participation restrictions and impairments, one study reported that the HRQoL of adolescents who were born premature did not differ significantly from their full-term peers (Saigal, 2013). Therefore, it seems that HRQoL is also affected by other factors, such as socioeconomic status than the severity of the disease.

In a systematic review on quality of life of former premature children, Zwicker and Harris (2008) also noticed a difference in child-health reports where the effects of preterm birth/very low birth weight on health-related quality of life seem to diminish over time (Zwicker and Harris, 2008). This is further confirmed by other studies where it is believed that child-parent views of Quality of life seem to differ, difference in personal opinions of HRQoL definitions and an individual's adaptation of his/her circumstances (Wolke, 1998; Laucht et al., 2000; Vederhus et al., 2010; Payot and Barrington, 2011; Hack et al., 2012).

The E-Q-5-D-Y was completed by the children in this study, with assistance from research assistants. Studies suggest that parents and teachers usually give lower scores to former premature children, than what these children scored themselves, showing a difference in HRQoL perspectives (Wolke, 1998; Laucht et al. 2000; Vederhus et al., 2010; Payot and Barrington, 2011; Hack et al., 2012). It is believed that children show a more positive outlook on life than adults, have overcome their limitations to a functioning level where they are comfortable and understand, with value and meaning. The reason for the difference in opinions could be that children seem to focus more on what they can do rather than on how standard tests compare them to the 'normal' of society. It would seem that children of premature birth have adapted and compromised to some aspects of quality of life and therefore have a high opinion of their HRQoL (Vieira and Linhares, 2011). However, the results of this study suggests that their views are still lower than the FT children.

## **5.4 Emotional-Behavioural Profile**

Advances in medical care have greatly benefitted very preterm and extremely premature children. Despite this, literature still shows major concerns in the behavioural outcomes of children born prematurely (Simms et al., 2013). This group of premature infants exhibits more problems such as ADD, ADHD, hyperactivity and anxiety impairments (Hutchinson et al. 2013). Due to early intervention programs, major deficits (such as cerebral palsy and other physical impairments) might have decreased in severity, leaving children with more social, behavioural challenges and psychiatric disorders (Laucht, Esser, Schmidt, 1997; Vohr et al., 2000; Laucht et al. 2000; Hogan and Park, 2000; Saigal, 2007). Results from the SDQ-teacher and parent versions, confirm lower scores in emotional and hyperactivity problems which has an impact on classroom learning. Importantly, there were no differences in the total scores across the levels of prematurity in either responses of the parents or the teachers.

### **5.4.1 Prosocial and Emotional behaviours**

According to both parents and teachers, there was a trend for FT and PREM groups to be significantly different in terms of prosocial behaviour scores. The impact of behaviour on class room function, teachers noted significant differences between the PREM and FT groups whereas parents did not think there were differences. Teachers reported differences between FT and PREM groups in terms of emotional scores and prosocial behaviour scores. Further reported teachers the PREM group to have significantly lower score rankings in more items, including the Emotional, Total Impairments and behaviour in class items. Literature (Delobel-Ayoub et al., 2006; Farooqi, 2008) indicate definitive behaviour problems in extremely premature children at the age of 6 years, this is normally associated with medical conditions such as poor health and major cerebral lesions (GMFCS level III, IV and V). (Delobel-Ayoub et al., 2006). This could not be proven in this study, as the strict exclusion criteria focussed on children with relative good health and GMFCS levels I and II.

Parents/caregivers seemed to think that these difficulties (emotional, conduct, hyperactivity, peer and prosocial problems) did not have an impact on their children's friendships, classroom learning, and leisure activities or in their home life. However, teachers did feel that these difficulties have an influence on classroom learning.

#### **5.4.2 Peer relationships**

Currently, literature confirm a difference in temperament of premature children at an early age (Langkamp, Kim, Pascoe, 1998; Hughes et al., 2002; Allin et al., 2006; Johnson, 2007; Schmidt et al., 2008). Wolke (1998) found that VLBW children admitted that they might have more peer relationship challenges unaware about social concerns from their parents as well (Wolke, 1998).

Our results showed no difference between FT and premature groups in terms of peer relations as reported by either parents ( $p=0.73$ ) or teachers ( $p=0.24$ )

#### **5.4.3 Conduct and prosocial behaviour**

There were no statistical difference in conduct between full term and premature children in this study. Saigal (2007) indicates that premature/low birth weight survivors will have difficulty with social competence rather than conduct disorders (Saigal, 2007). Contradicting Saigal in follow-up studies, Samara and colleagues from the EPICure study group (2008) agree with Farooqi (2008) on the presence of conduct problems in prematurely born children and how it form a link with cognitive deficits (Farooqi, 2008; Samara, Marlow, Wolke, EPICure study group, 2008).

#### **5.4.4 Hyperactivity and emotional problems**

Hyperactivity disorder is the most the prevalent and most studied of the psychiatric disorders in premature and low birth weight children (Saigal, 2007; Johnson and Marlow, 2011). Both the parents and teachers in previous research studies (Saigal 2007) agree that children are more overactive and fidgety in the foundation primary phase. There were no statistical difference in hyperactivity behaviour between full term and premature children in this study.

#### **5.4.5 Difference between teacher and parent reports**

The results from the teachers indicate a difference in opinion between children in a class situation. Teachers are more aware of peer problems in school as they spend more time with a child in a class with 30 other children. Research results from the total difficulties scores according to behavioural problems, did not indicate a major difference between parents and teachers' opinions.

## **5.5 Limitations of the current study**

The following limitations were identified: The overall sample size of the group was adequate for comparing full term children with premature children in the mainstream school system, but too small in terms of comparing within the premature group which limits the generalizability factors of results of this special population. In future, it is advisable that researchers use a larger sample within the premature group. Small sample sizes need to be interpreted with care, as the statistical power might be affected.

Another key issue is that this was a cross sectional study. Cross-sectional studies capture a population in a single point in time. In this research, we don't know what happened and all the factors that may have had an effect from birth to time that you assessed the children. It may not even be the prematurity that was a factor as association does not imply causation.

The study was limited to children born at term and children of premature birth in the Bloemfontein area and a radius of 100 km – this limits the study results from generalizing results, assumptions and conclusions. It is suggested that the study should include the whole Free State province and later all provinces to give a clear and better picture on the provincial and national motor function and HRQoL status of all learners in the foundation phase. This will provide a more reliable picture of premature children and their long term outcomes in South Africa.

Children with severe physical disability were excluded (GMFCS level III and IV) thus giving an incomplete view of the problems associated with prematurity. It is recommended that a cross cutting assessment of motor function be used such as the Wii FIM to capture mild and severe motor problems.

The findings of this study confirm expectations that the full term group was to a lesser extent affected by the neonatal complications and variables. More premature and lower birth weight infants were associated with the incidence of perinatal variables such as low birth weight, anti-natal steroids, supplemental oxygen and frequency of hospitalisation.

This research further indicated grade 1, 2 haemorrhaging to be still a big factor for concern. More focus should be to the moderate to very premature groups, as they highlighted concerns in age-appropriate motor tasks shown with the MABC-2 and MABC-checklist. DCD were also a concern in the LBW and  $\geq 2500\text{g}$  weight groups as measured by the MABC-2 and the checklist from teachers. SDQ-parent version indicated more emotional and hyperactivity in the late and moderate to very preterm groups. The SDQ-teacher version showed more emotional, hyperactivity and peer problems in the premature group. Teachers felt that these behavioural problems did have an impact on class room learning.

## 6 CONCLUSIONS

The purpose of the study was to determine if there is a difference in motor function and HRQoL and behaviour of premature children compared to their full term peers in a mainstream school system, specifically when they enter the school system. Our findings suggest that premature children have more functional motor performance deficits, lower health related quality of life in the mobility domain and overall VAS and more emotional-behavioural problems than their full term peers. Our findings suggest no major differences in these domains between prematurity groups in this research.

The FT group scored higher than the PREM group on the overall MABC-2 TSS and lower than the PREM group on the checklist (low score=better performance). Poorer motor performance and function was associated with prematurity with 23 children in the PREM group (37.7 %) categorised as red or amber on the MABC-2, compared to 10 (16.4 %) in the FT group on the MABC-2 classification. Although the MABC-2 was used in this research on children with mild CP, attending mainstream schools, the MABC-2 is not a suitable measure for children with CP. It might be feasible to alter the MABC-2 to accommodate all premature children, in order to determine a more accurate motor performance of a premature child with any form of motor impairment.

It is evident that children born preterm have variations in their motor development compared with peers born at term, however motor performance was not associated with degree of prematurity as there were no significant differences in overall motor between groups ( $p=0.095$ ). It is therefore essential to understand and distinguish the range of motor impairments experienced by children born preterm so that the most appropriate interventions can be implemented early.

There was no association found between group and any domain of the E-Q-5-D-Y, apart from mobility. Suggesting that PREM children do not generally report more problems than FT children. However their VAS scores were generally lower, indicating lower HRQOL.

Parents and Teachers reported slightly different findings regarding emotional-behavioural profiles of children. Teachers reported the PREM group to have significantly lower score rankings in more items, including the Emotional, Total Impairments and behaviour in class items. Both parents and teachers identified differences in prosocial behaviour. However, there was no difference in the total scores between the PREM and FT groups by either group of respondents. There was also no difference between the scores of the different levels of prematurity by either group of respondents

Disabilities or problems can be subtle and numerous, therefore this research study shed light on some of the long-term effects of prematurity on a child's life during their foundation school phase. This study

has provided new insights on the problems experienced by this group and in contrast to other studies shows very little differences between degrees of prematurity. Findings from this study reflect on previous perceived ideas that only gestation will determine long term outcomes; the focus has shifted more to low birthweight infants and their immature brains, rather than their gestation. Although there were motor deficits, it was clear that long term psychiatric problems resulting in an accumulation of emotional-behavioural issues, will be a bigger challenge to prevent, address and treat.

### **6.1.1 Clinical Recommendations:**

Currently, there is a greater interest and more effort are made in how to accommodate these social and behavioural challenges seen in premature children (Laucht et al., 1997; Vohr et al., 2000; Laucht et al. 2000; Hogan and Park, 2000; Saigal, 2007). Saigal, (2007) suggests that parents/caregivers should be better informed on possible behavioural disorders and health care professionals need to focus on early diagnosis (Saigal, 2007).

This findings of this research clearly support the need for more specific interventions. With the increased numbers of this at risk population entering society, continuous monitoring and identification of educational-specific therapy programs will help to minimise long term secondary problems. The behavioural problems exhibited by premature need to be earlier identified with systematic follow-up of school age-children in order to minimise future predicaments of behavioural disorders. There should be an increased awareness of low risk children, with subtle and minor deficits, as they are the ones that are normally over looked.

It is envisaged that the outcomes of this research will benefit and interest both healthcare professionals, parents/caregivers and teachers that are working to make a difference in these children's lives. It will assist teachers to understand and be more aware of the needs of children who were born prematurely. Physiotherapists and neonatal personnel will be made more aware of possible neonatal factors that may contribute to poor motor function and health related quality of life later in a premature child's life. It will help to minimise the stigma of negative outcomes of these children. Predictions on the long-term outcome of different premature infants will allow earlier adaptations. The data obtained will be used to draw conclusions about the impact prematurity has on the quality of life of premature infants later in their lives.

Precise identification of possible perinatal and neonatal risk factors will ensure better future outcomes as these risk factors may in some way be prevented or modified. Thomaidis et al. (2014) confirm prematurity and intrauterine growth restriction to be significant predictors in the outcome of age-specific developmental delays (Thomaidis et al., 2014).



Various questions still remain unanswered: What is the extent and effect of these mentioned limitations on a child's school career and adulthood (Bhutta et al., 2002). Will limitations persist and till when? Will therapeutic interventions and medication help to minimise limitations? Are age appropriate motor control and health related quality of life deficits in the foundation phase going to persist throughout a child's school career?

There needs to be more awareness and focus on the problems experienced by premature/ children. If early detection of any future deficits and identification of modifiable factors can be anticipated sooner rather than later, it will be beneficial to look at age-appropriate and specific intervention programmes to ensure better outcomes (Moster and Markestad, 2008). This will decrease future costs of rehabilitation, special education needs and provide this at risk population with a higher quality of life.

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## 8 APPENDICES

### 8.1 Appendix I: Self-designed questionnaire:

Maternal Demographic Risk Factors	Neonatal Complications of Prematurity
Age: _____ years	Respiratory Distress: Yes No <input type="checkbox"/> <input type="checkbox"/>
Marital status: Single Married Divorced Widow <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Domestic Partners <input type="checkbox"/>	Serum-Bilirubin: Yes No (> 10 mg/dl) <input type="checkbox"/> <input type="checkbox"/>
Habits during pregnancy: Yes No Smoking <input type="checkbox"/> <input type="checkbox"/> Alcohol <input type="checkbox"/> <input type="checkbox"/> Substances <input type="checkbox"/> <input type="checkbox"/>	Apnoea of Prematurity: Yes No <input type="checkbox"/> <input type="checkbox"/>
Medical History: Yes No Diabetes Mellitus <input type="checkbox"/> <input type="checkbox"/> Hypertension <input type="checkbox"/> <input type="checkbox"/> Asthma <input type="checkbox"/> <input type="checkbox"/> Other: _____	Necrotizing Enterocolitis (NEC): Yes No <input type="checkbox"/> <input type="checkbox"/>
Previous Pregnancies: Number of alive babies: <input type="checkbox"/> Miscarriages: <input type="checkbox"/> Intra-uterine deaths: <input type="checkbox"/> Previous premature babies: <input type="checkbox"/>	Patent Ductus Arteriosus (PDA): Yes No <input type="checkbox"/> <input type="checkbox"/>
Education: No schooling <input type="checkbox"/> Primary School <input type="checkbox"/> High School <input type="checkbox"/> Grade 12 <input type="checkbox"/> Tertiary <input type="checkbox"/>	Septicaemia: Yes No <input type="checkbox"/> <input type="checkbox"/>
	Haemorrhaging: Yes No <input type="checkbox"/> <input type="checkbox"/> Grade 1,2 <input type="checkbox"/> Grade 3,4 <input type="checkbox"/> Ventricular Dilatation <input type="checkbox"/>
	Surgery in the new-born period: Yes No <input type="checkbox"/> <input type="checkbox"/> Specify: .....

**Retinopathy of Prematurity:** Yes No  
☐ ☐

**Post-Natal Steroids:** Yes No  
☐ ☐

**Perinatal variables**

**Weight (g):** \_\_\_\_\_ grams

**Gestation (weeks):** \_\_\_\_\_

**Sex:** Male Female  
☐ ☐

Singleton Twins Triplets More  
☐ ☐ ☐ ☐

**Apgar Score:**

1 min 5 min  
☐ ☐

**Antenatal Steroids:** Yes No  
☐ ☐

**Delivery:**

Normal Vaginal Delivery ☐  
Assisted Delivery ☐  
Caesarean Section ☐

**Measures of Chronic Disease:**

**Supplemental Oxygen:** Yes ☐ No ☐

**Ossilation:** Yes ☐ No ☐

**Mechanical Ventilation:** Yes ☐ No ☐

**Oxygen Dependence at**

**36 Weeks Hospital stay (in-hospital O2 dependence):**

**Yes / No** ☐ ☐

**Post-discharge healthcare:**

**Frequency of Hospitalization:**

(average admissions per year)

Once/year Yes ☐ No ☐  
Twice and more Yes ☐ No ☐

**Therapy:**

Physiotherapy ☐  
Occupational therapy ☐  
Speech therapy ☐  
Other ☐

**Impairments:**

Vision: ☐  
Hearing: ☐

Other: \_\_\_\_\_

## 8.2 Appendix II: Movement Assessment Battery (Movement ABC-2):

Form: Movement Assessment Battery for children; Age band 1 (3-6 years)

Name: ..... Gender: male/female ID number: .....

School: ..... Class/Grade: ..... Tester: .....

Preferred writing hand: Right/left

Determining age:

	Year	Month	Day
Test date			
DOB			
Age			

### Item 1: Posting Coins

	Writing hand	Other hand		
Trial 1	s	S	ISS best hand =	
Trial 2	s	S	ISS other hand =	Mean ISS 1 =

### Item 2: Threading beads on string

	Number of sec	
Trial 1	s	ISS 2 =
Trial 2	s	

### Item 3: Drawing trial

	Number of mistakes	
Trial 1		ISS 3 =
Trial 2		

Cluster Score =

### Item 4: Catching beanbag

Total correct = ISS 4 =

**Item 5: Throw beanbag  
on mat**

Total correct =

ISS 5 =

Cluster Score =

**Item 6: One leg stance**

	R-leg	L-leg		
Trial 1	s	s	ISS best item 6 =	
Trial 2	s	s	ISS other =	Mean ISS 6 =

**Item 7: Walk on toes**

	Nr	of	Whole	
	steps		line	
Trial 1			Yes/No	
Trial 2			Yes/No	ISS 7 =

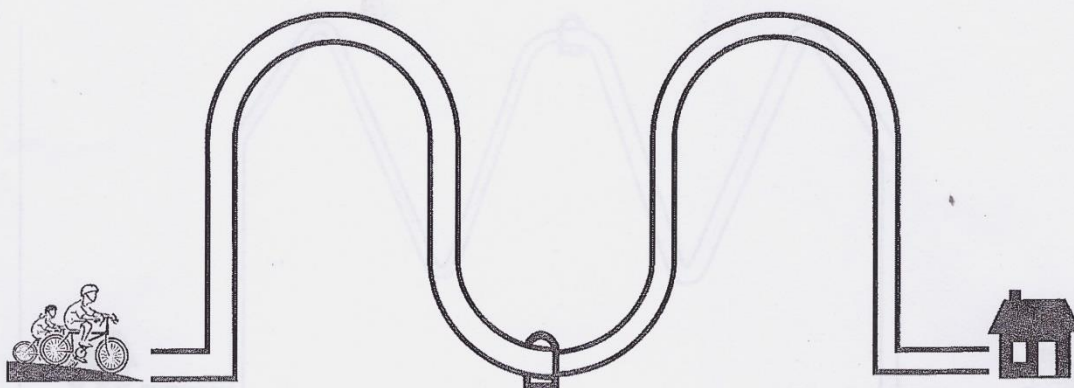
**Item 8: Jump on mats**

	Nr	of		
	jumps			
Trial 1				
Trial 2				ISS 8 =
			Cluster Score =	

<b>Total Test Score (ISS 1-8)</b>	<b>Standard Score</b>	<b>Percentile Score</b>	<b>Red/Orange/Green</b>
-----------------------------------	-----------------------	-------------------------	-------------------------

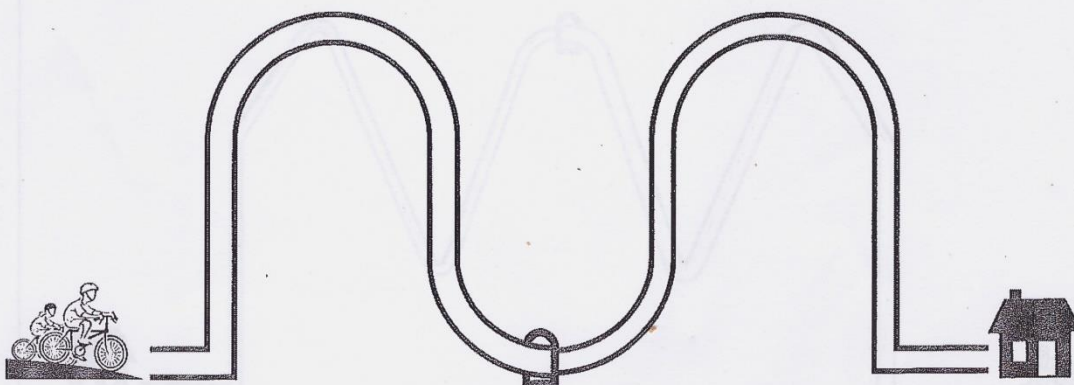
LB1 Oefening

Naam: \_\_\_\_\_



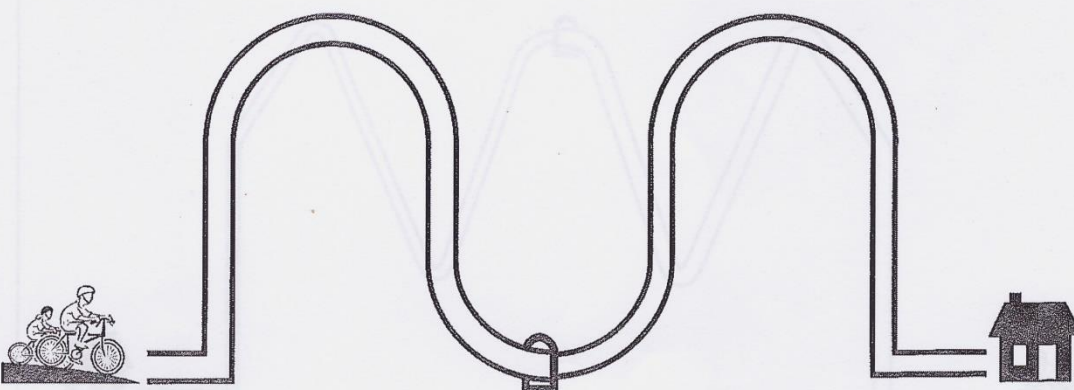
LB1 Poging 1

Naam: \_\_\_\_\_



LB1 Poging 2

Naam: \_\_\_\_\_





### 8.3 Appendix III: Movement Assessment Battery (Movement ABC-2)

Form: Movement Assessment Battery for children; Age band 2 (7-10 years)

Name: ..... Gender: male/female ID number: .....

School: ..... Class/Grade: ..... Tester: .....

Preferred writing hand: Right/left

Determining age:

	Year	Month	Day
Test date			
DOB			
Age			

Item 1: Placing Pegs				
	Writing hand	Other hand		
Trial 1	s	S	ISS best hand =	
Trial 2	s	S	ISS other hand =	Mean ISS 1 =
Item 2: Threading Lace				
	Number of sec			ISS 2 =
Trial 1	s			
Trial 2	s			
Item 3: Drawing trial				
	Number of mistakes			ISS 3 =
Trial 1				
Trial 2				
			Cluster Score =	

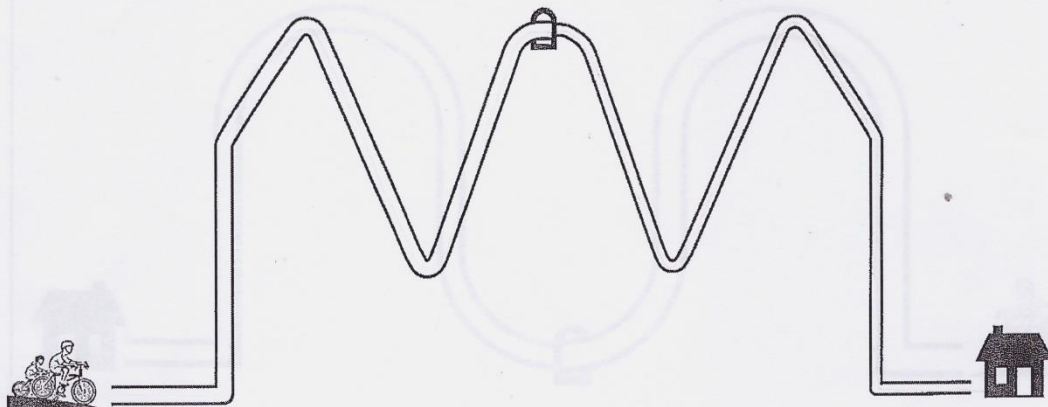
Item 4: Catching with two hands				
Total correct =				ISS 4 =

<b>Item 5: Throw beanbag on mat</b>				
Total correct =				ISS 5 =
			Cluster Score =	
<b>Item 6: One board balance</b>				
	R-leg	L-leg		
Trial 1	s	s	ISS best item 6 =	
Trial 2	s	s	ISS other 6 =	Mean ISS 6 =
<b>Item 7: Walk heel to toe</b>				
	Nr of steps	Whole line		
Trial 1		Yes/No		
Trial 2		Yes/No		ISS 7 =
<b>Item 8: Hopping on mats</b>				
	R-leg	L-leg		
Trial 1	jumps	jumps	ISS best leg =	
Trial 2	jumps	jumps	ISS other leg =	Mean ISS 8 =
			Cluster Score =	

<b>Total Test Score (ISS 1-8)</b>	<b>Standard Score</b>	<b>Percentile Score</b>	<b>Red/Orange/Green</b>

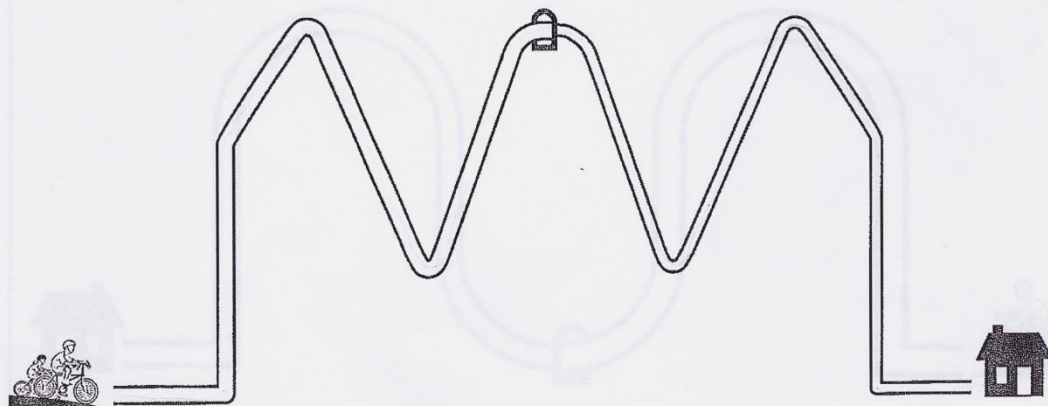
LB2 Oefening

Naam: \_\_\_\_\_



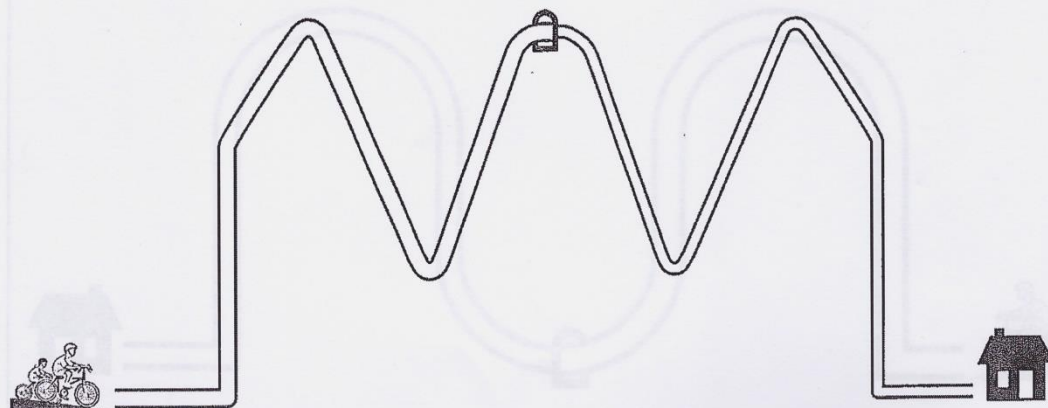
LB2 Poging 1

Naam: \_\_\_\_\_



LB2 Poging 2

Naam: \_\_\_\_\_



## 8.4 Appendix IV: MABC Checklist



# Movement Assessment Battery for Children – 2 Checklist

Name of Child: _____	Gender: M / F _____
Age: _____	Class/Grade: _____
School: _____	
Address: _____ _____ _____	
Name of Respondent: _____	
Profession: Teacher    Therapist    Parent    Other _____	
Date of Assessment: _____	

Red Zone	≥42							
Amber Zone	41							
	40	≥25	≥17					
	39			≥13	≥10			
	38	24	16			≥7		
	37	23	15	12	9		≥3	
	36	22	14	11	8	6		≥2
	35	21	13	10	7	5	2	
	34	20	12	9	6	4	1	1
Green Zone	33 or less	19 or less	11 or less	8 or less	5 or less	3 or less	0	0
Age	5	6	7	8	9	10	11	12

**Motor Competence:** Section A  Section B  Total Motor Score: A + B =

Find the child's Total Motor Score in the column appropriate for his/her age and determine whether it falls in the Red  Amber  or Green  zone (tick one)

### Non-motor factors that might affect movement

Do you think the characteristics noted in Section C prevent the child from demonstrating his/her true movement capability? (circle one): **not at all / a little / a great deal.**

How important will it be to consider these factors when planning an intervention programme? (circle one): **not at all / somewhat / very.**

*Form: Movement Assessment Battery for children; Checklist*

*Name:* ..... *Gender:* male/female *ID number:* .....

*School:* ..... *Class/Grade:* ..... *Tester:* .....

*Profession:* teacher/parent/caregiver

*Determining age:*

	Year	Month	Day
Test date			
DOB			
Age			

Section A: Movement in a static and/or predictable environment		
0 = very well, 1 = just OK, 2 = almost, 3 = not close, NO = not observed		
<b>A1</b>	<b>Self-care skills</b>	<b>score</b>
A1.1	Maintains balance while standing to pull on articles of clothing e.g. trousers, skirt	
A1.2	Puts on clothing over the head (t-shirt, sweater)	
A1.3	Fastens buttons (on shirt, coat)	
A1.4	Washes and dries hands	
A1.5	Pours liquid from one container to another (e.g. from a jug to a beaker)	
<b>A2</b>	<b>Classroom skills</b>	
A2.1	Manipulates small objects (e.g. blocks, beads, sheets of paper)	
A2.2	Forms letters using a pencil or pen	
A2.3	Uses scissors to cut paper	
A2.4	Walks around the classroom avoiding fixed/stationary objects and persons	
A2.5	Transports objects (e.g. books, pots of pens, etc) around the room without dropping them	
<b>A3</b>	<b>Recreational skills</b>	
A3.1	Jumps keeping two feet together on take-off and landing	
A3.2	Hops on either foot	
A3.3	Throws a beanbag or ball so that another stationary child can catch it	
A3.4	Uses stationary gym/playground equipment (e.g. climbing frame, slide)	
A3.5	Crosses the gym/playground avoiding collision with stationary objects/persons	
	<b>Section A TOTAL</b>	

<b>Section B: Movement in a dynamic and/or unpredictable environment</b>		
0 = very well, 1 = just OK, 2 = almost, 3 = not close, NO = not observed		
<b>B1</b>	<b>Self-care/classroom skills</b>	<b>score</b>
B1.1	Maintains balance when frequent adjustments are required (e.g. sitting on a bench then relocating as other children sit down, standing in a line among moving children)	
B1.2	Moves around a busy classroom collection in/giving out objects (e.g. books, pens)	
B1.3	Carries a tray/drink around a room avoiding moving persons (e.g. in the dining hall)	
B1.4	Keeps time to a musical beat by clapping hands or tapping feet	
B1.5	Moves body in time with music or other people (e.g. marches in line, dances in a group)	
<b>B2</b>	<b>Ball skills</b>	
B2.1	Catches a ball using a two-handed catch	
B2.2	Hits/strikes a moving ball using a bat or racquet	
B2.3	Throws a ball while on the move so that another child can catch it	
B2.4	Continually bounces and keeps control of a large playground ball	
B2.5	Participates in a team game using skills of throwing, catching, kicking or striking	
<b>B3</b>	<b>Recreational skills</b>	
B3.1	Rides a bicycle without stabilisers	
B3.2	Participates in dodging and chasing games	
B3.3	Maintains balance in water among other children (e.g. standing in the swimming pool)	
B3.4	Uses non stationary gym/playground equipment (e.g. swings, scooters)	
B3.5	Crosses the gym/playground avoiding collision with moving objects/persons	
	<b>Section B TOTAL</b>	

Section C: Non-motor factors that might affect movement		
Yes/No		
		score
C1	<i>Disorganised</i> (e.g. scattered clothes slows up dressing after PE; puts on shoes before socks)	
C2	<i>Hesitant/forgetful</i> (e.g. slow to start complex actions; forgets what to do in the middle of an action sequence)	
C3	<i>Passive</i> (e.g. hard to interest; requires much encouragement to participate)	
C4	<i>Timid</i> (e.g. fearful of activities such as jumping/climbing; constantly asks for assistance)	
C5	<i>Anxious</i> (e.g. trembles; becomes flustered in a stressful situation)	
C6	<i>Impulsive</i> (e.g. starts before instructions are complete; impatient of detail)	
C7	<i>Distractible</i> (e.g. looks around; responds to irrelevant noises)	
C8	<i>Overactive</i> (e.g. squirms and fidgets; moves constantly when listening to instructions, fiddles with clothes)	
C9	<i>Overestimates own ability</i> (e.g. tries to make tasks more difficult; tries to do things too fast)	
C10	<i>Underestimates own ability</i> (e.g. complains of task difficulty; anticipates failure before starting)	
C11	<i>Lacks persistence</i> (e.g. gives up quickly; is easily frustrated)	
C12	<i>Upset by failure</i> (e.g. looks tearful; refuses to try task again)	
C13	<i>Unable to get pleasure from success</i> (e.g. fails to respond to praise)	
	<b>TOTAL Yes</b>	
	<b>TOTAL No</b>	



## 8.5 Appendix V: Strength and Difficulties Questionnaire - Parent version:

**Area Logo**

**PC1**

Parent Report Measures for  
Children and Adolescents  
SDQ(P)04-10

Facility Name: \_\_\_\_\_

Code: \_\_\_\_\_

Please used gummed label if available

Patient or Client Identifier:

Surname: \_\_\_\_\_

Other names: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Sex:

\_\_\_\_ / \_\_\_\_ / \_\_\_\_

Male ☐

Female ☐

Address: \_\_\_\_\_

**Instructions:** For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months**.

Strengths and Difficulties Questionnaire	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Restless, overactive, cannot stay still for long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Often complains of headaches, stomach-aches or sickness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Shares readily with other children, for example toys, treats, pencils	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Often loses temper	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Rather solitary, prefers to play alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Generally well behaved, usually does what adults request	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Many worries or often seems worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Helpful if someone is hurt, upset or feeling ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Constantly fidgeting or squirming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Has at least one good friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Often fights with other children or bullies them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Often unhappy, depressed or tearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Generally liked by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Easily distracted, concentration wanders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Nervous or clingy in new situations, easily loses confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Kind to younger children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Often lies or cheats	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Picked on or bullied by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Often volunteers to help others (parents, teachers, other children)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Thinks things out before acting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Steals from home, school or elsewhere	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Gets along better with adults than with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Many fears, easily scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Good attention span, sees chores or homework through to the end	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SDQ (P) 04-10 SELF-REPORT MEASURE (1 of 2)

SOURCE: Mental Health National Outcomes and Casemix Collection: Overview of Clinician-Rated and Consumer Self-Report Measures V1.50, Mental Health & Suicide Prevention Branch, Department of Health and Ageing



Please turn over – there are a few more questions on the other side

Do you have any other comments or concerns?

Over the last six months, have your child's teachers complained of:		No	A Little	A Lot
36.	Fidgetiness, restlessness or overactivity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37.	Poor concentration or being easily distracted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38.	Acting without thinking, frequently butting in, or not waiting for his or her turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No	Yes – minor difficulties	Yes – definite difficulties	Yes – severe difficulties
26 Overall, do you think that your child has difficulties in any of the following areas: emotions, concentration, behaviour or being able to get along with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have answered "Yes", please answer the following questions about these difficulties:

	Less than a month	1-5 months	6-12 months	Over a year
27 How long have these difficulties been present?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little	A medium amount	A great deal
28 Do the difficulties upset or distress your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do the difficulties interfere with your child's everyday life in the following areas?				
29. HOME LIFE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. FRIENDSHIPS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. CLASSROOM LEARNING	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. LEISURE ACTIVITIES	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33 Do the difficulties put a burden on you or the family as a whole?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Signature \_\_\_\_\_ Date \_\_\_\_\_

Mother/Father/Other (please specify): \_\_\_\_\_

**Thank you very much for your help.**

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SOURCE: Mental Health National Outcomes and Casemix Collection: Overview of Clinician-Rated and Consumer Self-Report Measures V1.50, Mental Health & Suicide Prevention Branch, Department of Health and Ageing



## 8.6 Appendix VI: Strength and Difficulties Questionnaire - **Teacher** version:

**Area Logo**

**TC1**

Teacher Report Measures for  
Children and Adolescents  
SDQ(T)04-10

Facility Name: \_\_\_\_\_

Code: \_\_\_\_\_

Please use gummed label if available

Patient or Client Identifier:

Surname:

Other names:

Date of Birth:

Sex:

\_\_\_\_/\_\_\_\_/\_\_\_\_

Male ☐

Female ☐

Address:

**Instructions:** For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of the child's behaviour **over the last six months or this school year**.

Strengths and Difficulties Questionnaire		Not True	Somewhat True	Certainly True
1.	Considerate of other people's feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	Restless, overactive, cannot stay still for long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	Often complains of headaches, stomach-aches or sickness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	Shares readily with other children, for example toys, treats, pencils	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	Often loses temper	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	Rather solitary, prefers to play alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	Generally well behaved, usually does what adults request	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	Many worries or often seems worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	Helpful if someone is hurt, upset or feeling ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	Constantly fidgeting or squirming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	Has at least one good friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12.	Often fights with other children or bullies them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	Often unhappy, depressed or tearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	Generally liked by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15.	Easily distracted, concentration wanders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	Nervous or clingy in new situations, easily loses confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	Kind to younger children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18.	Often lies or cheats	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19.	Picked on or bullied by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20.	Often volunteers to help others (parents, teachers, other children)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21.	Thinks things out before acting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.	Steals from home, school or elsewhere	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.	Gets along better with adults than with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24.	Many fears, easily scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25.	Good attention span, sees chores or homework through to the end	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SDQ (T) 04-10 SELF-REPORT MEASURE (1 of 2)

Please turn over – there are a few more questions on the other side

SOURCE: Mental Health National Outcomes and Casemix Collection: Overview of Clinician-Rated and Consumer Self-Report Measures V1.50, Mental Health & Suicide Prevention Branch, Department of Health and Ageing

Do you have any other comments or concerns?

	No	Yes – minor difficulties	Yes – definite difficulties	Yes – severe difficulties
26 Overall, do you think that this child has difficulties in any of the following areas: emotions, concentration, behaviour or being able to get along with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have answered "Yes", please answer the following questions about these difficulties:

	Less than a month	1-5 months	6-12 months	Over a year
27 How long have these difficulties been present?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little	A medium amount	A great deal
28 Do the difficulties upset or distress the child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do the difficulties interfere with the child's everyday life in the following areas?				
30. PEER RELATIONSHIPS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. CLASSROOM LEARNING	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33 Do the difficulties put a burden on the class as a whole?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Signature \_\_\_\_\_ Date \_\_\_\_\_

**Thank you very much for your help**

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SDQ (T) 04-10 SELF-REPORT MEASURE (2 of 2)

SOURCE: Mental Health National Outcomes and Casemix Collection: Overview of Clinician-Rated and Consumer Self-Report Measures V1.50, Mental Health & Suicide Prevention Branch, Department of Health and Ageing

## 8.7 Appendix VII: EQ-5D-Y:

### Describing your health TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

#### **Mobility** (*walking about*)

- I have no problems walking about ☐
- I have some problems walking about ☐
- I have a lot of problems walking about ☐

#### **Looking after myself**

- I have no problems washing or dressing myself ☐
- I have some problems washing or dressing myself ☐
- I have a lot of problems washing or dressing myself ☐

#### **Doing usual activities** (*for example, going to school, hobbies, sports, playing, doing things with family or friends*)

- I have no problems doing my usual activities ☐
- I have some problems doing my usual activities ☐
- I have a lot of problems doing my usual activities ☐

#### **Having pain or discomfort**

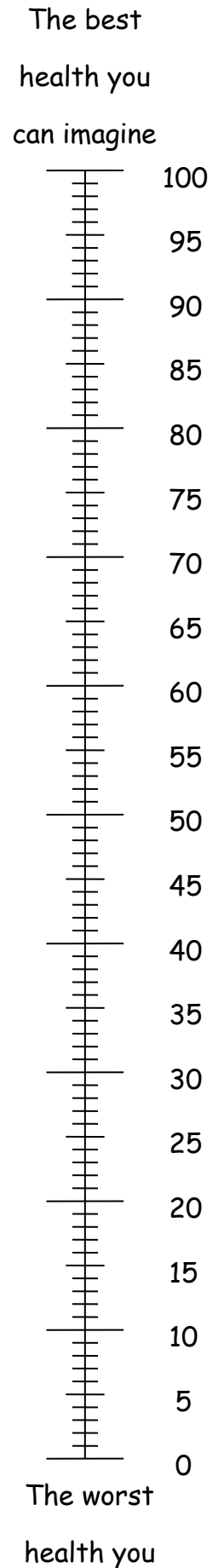
- I have no pain or discomfort ☐
- I have some pain or discomfort ☐
- I have a lot of pain or discomfort ☐

#### **Feeling worried, sad or unhappy**

- I am not worried, sad or unhappy ☐
- I am a bit worried, sad or unhappy ☐
- I am very worried, sad or unhappy ☐

**How good is your health TODAY**

- We would like to know how good or bad your health is TODAY.
- This line is numbered from 0 to 100.
- 100 means the best health you can imagine.  
0 means the worst health you can imagine.
- Please mark with an X on the line to show how good or bad your health is TODAY.





## 8.8 Appendix VIII: Consent forms

### Consent form for parents/guardians of children having a history of premature birth

I, Henriette Tredoux (researcher) have fully explained to \_\_\_\_\_ (parent/guardian) the purpose of this study which is to identify factors that influence quality of life in children having a history of premature birth and how they compare to their peers in the same grade. I have tried to answer all possible questions that may concern the parents/guardians and to explain and clarify all procedures, risks and benefits involved in this study. I have answered and will answer all questions to the best of my ability. I will inform the parents/guardians of any changes in the procedure or the risks and benefits if any should occur during or after the course of the study. I also informed them about the time schedule for each questionnaire and procedure.

\_\_\_\_\_  
Henriëtte Oosthuizen (Tredoux)

Researcher

(0823350234)

[htredoux@yahoo.com](mailto:htredoux@yahoo.com)

I \_\_\_\_\_ (parent/guardian) have been satisfactorily informed about the purpose of this study as well as the procedure, risks and benefits. I hereby give permission for my child's participation in this study. I know that Henriëtte and her associates will be available to answer any questions I may have. I understand that participation is voluntary and I am free to withdraw this consent and discontinue participation in this project at any time and it will not affect my child's care. I was informed that there will be no financial or other remuneration if I participate in this study. I was informed that the testing will not take longer than an hour of my time. The purpose of every questionnaire was clearly explained to me and I understand the importance of my participation.

I have been offered a copy of this form.

\_\_\_\_\_  
Witness signature

\_\_\_\_\_  
Parent/Guardian

### **Consent form for parents/guardians of full term children**

I, Henriette Tredoux (researcher) have fully explained to \_\_\_\_\_ (parent/guardian) the purpose of this study which is to identify factors that influence quality of life in children having a history of premature birth and how they compare to their peers in the same grade. I have tried to answer all possible questions that may concern the parents/guardians and to explain and clarify all procedures, risks and benefits involved in this study. I have answered and will answer all questions to the best of my ability. I will inform the parents/guardians of any changes in the procedure or the risks and benefits if any should occur during or after the course of the study. I also informed them about the time schedule for each questionnaire and procedure.

\_\_\_\_\_  
Henriëtte Oosthuizen (Tredoux)

Researcher

(0823350234)

[htredoux@yahoo.com](mailto:htredoux@yahoo.com)

I \_\_\_\_\_ (parent/guardian) have been satisfactorily informed about the purpose of this study as well as the procedure, risks and benefits. I hereby give permission for my child's participation in this study. I know that Henriëtte and her associates will be available to answer any questions I may have. I understand that participation is voluntary and I am free to withdraw this consent and discontinue participation in this project at any time and it will not affect my child's care. I was informed that there will be no financial or other remuneration if I participate in this study. I was informed that the testing will not take longer than an hour of my time. The purpose of every questionnaire was clearly explained to me and

I understand the importance of my participation.

I have been offered a copy of this form.

\_\_\_\_\_  
Witness signature

\_\_\_\_\_  
Parent/Guardian

### **Consent form for teachers**

I Henriette Tredoux (researcher) have fully explained to \_\_\_\_\_ (teacher) the nature and purpose of this study which is to identify factors that influence quality of life in children having a history of premature birth and how they compare to their peers in the same grade. I have tried to answer all possible questions that may concern the teachers. I have explained and clarified all procedures, risks and benefits involved in this study. I have answered and will answer all questions to the best of my ability. I will inform all teachers involve of any changes in the procedure or the risks and benefits if any should occur during or after the course of the study. I also informed them about the time schedule for each questionnaire and procedure.

\_\_\_\_\_  
Henriëtte Oosthuizen (Tredoux)

Researcher

(0823350234)

[htredoux@yahoo.com](mailto:htredoux@yahoo.com)

I \_\_\_\_\_ (teacher) have been satisfactorily informed of the above-described procedure with its possible risks and benefits. I hereby give permission for my own participation in this study for the completion of a questionnaire that involves some of the children in my class. I will complete every questionnaire honestly and to the best of my knowledge to help the accuracy of the results. I know that Henriëtte and her associates will be available to answer any questions I may have. I understand that participation is voluntary and I am free to withdraw this consent and discontinue participation in this project at any time and it will not affect my career or relationship with colleagues and parents. I was informed that there will be no financial or other remuneration if I participate in this study. I am aware that this study will not take more than an hour of my time after school. I have been offered a copy of this form.

\_\_\_\_\_  
Witness signature

\_\_\_\_\_  
Teacher



## **Confidentiality agreement**

**Research title:** *“The association between prematurity, motor function and health related quality of life among learners in the foundation primary phase.”*

This confidentiality agreement is entered into by..... (*teacher/assistant/tester*) and between H Tredoux (researcher) for the purpose of preventing the unauthorized disclosure of confidential information as defined below. The researcher must take every means possible to protect the identity of the research participants and preserve the confidentiality of information obtained during this research. I ..... (teacher/assistant/tester) agree to the following aspects of this research:

- I understand that all the material I will be asked to record is confidential.
- I understand that the contents of the consent forms, questionnaires and MABC-2 can only be discussed with the researcher.
- I will not keep any copies of the information nor allow third parties to access them.
- I shall only disclose the confidential information if required to do so by law.

The parties acknowledge that they have read and understand this agreement and voluntarily accept the duties and obligations set forth herein.

Research tester/assistant/teacher's name: \_\_\_\_\_

Research tester/assistant/teacher's signature: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's name: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

*Note: The research assistant/teacher will be given a copy of this form to retain for her/his records*

## 8.9 Appendix IX: Assent Form

### *Assent form for children having a history of premature birth (to be read out to participants by tester)*

The study will be explained to the children in an age appropriate manner and they will be given the opportunity to sign assent or to dissent. Assent will be obtained at the school after the families have been visited at their homes to explain the study to them.

#### ***Request to participate in a research study:***

My name is Henriëtte Oosthuizen (Tredoux). I am a physiotherapist in private hospitals in Bloemfontein. I am writing a paper about children being born earlier than expected. I have found your name from your school records. Your parents gave me permission to ask you if you want to take part in a few activities and answer some questions about your life.

#### ***Why do I want you to take part in this study?***

We want to know if children who are born early are happy with different things in their life such as moving around, taking care of themselves and their feelings.

Therefore we have come to your school to see how easy you find these activities and to watch how you do different things.

#### ***What do you have to do?***

We will ask you to do some physical activities from a game (the *Movement ABC-2*). The activities will be familiar to you, it will include placing pegs, threading lace, drawing on a line, catching, throwing a bean bag, standing on one leg, hopping in squares and walking with your feet behind each other.

You do not have to worry about reading the questions, a trained person will assist you and explain each question and activity to you so that it is clear to you. No one else will be able to see how you scored in the activities.

Furthermore will you also be asked to complete the EQ-5D-Y questionnaire about how you see your current health.

You will do the different activities and the questionnaire individually with the tester in the gym area, no other children will be there.

#### ***What do your parents/guardians have to do?***

While the researchers are busy with you, your parents/guardians will be asked to fill in the

*Strengths and Difficulties Questionnaire for parents.* This questionnaire will tell us more about your feelings and emotions (happy, sad, and angry).

Your parents/caregivers will be completing the questionnaires in a classroom in the company of a different tester.

***What do your teachers have to do?***

Your grade R, 1 or 2 teachers play a big part in this study, since they are in contact with you a big part of the day and might experience you different from your parents/guardians. Therefore they will be asked to complete the *Strengths and Difficulties questionnaire* about their experience of some of you in terms of behaviour and emotional difficulties. They will also be asked to complete the *Movement Assessment Battery for children's checklist* (MABC-checklist). This questionnaire will tell us about your functional classroom and playground movement (how you move around in class and outside).

Your teacher will be in another classroom with a different tester, completing their set of questionnaires about you.

***When will these tests take place?***

All of this will happen after school hours in your classroom and the gym area of your school. All the questionnaire and activity tests will only take about an hour of your time. It will not prevent you from doing homework or taking part in sports or any other activities that you might have.

***How long will it take?***

Answering these questions will only take about 20 minutes. The physical activities will take about 20 – 40 minutes of your time.

***What happens after the tests?***

If we see that there are some areas that you find a bit difficult, we will inform your parents/guardians and we will make sure you get the assistance you need to help you overcome the problem.

***Who will know the outcome of the tests?***

Only your parents will receive the results of their child. It is their decision and if they want to share the results with your teacher.

***Can you refuse to take part in this study?***

You are free to say no, even if you parents have already agreed. Even if you start you can still stop at any time you want to, your teachers and I will not hold it against you. You may also ask any questions about this study.

***What about privacy?***

If you decide to take part in this study, I am not allowed to tell anyone what you said or wrote on your paper. Even if your parents, teachers or friends ask me what you wrote, I will not tell them. Participation to this study is completely your own choice; no one can force you to participate. You will not receive any money or gifts to take part in this study. Only your parents/caregivers will receive your results. It is their decision and discretion if they want to share the results with your teacher.

***What are the risks involved in this study?***

It may be difficult for you and your parents/guardians to learn that you are struggling with some activities; therefore we will refer you to the school social worker or psychologist for counselling and support. .You will also be referred to another therapist to confirm what we found in the questionnaires and the activities and to help you.

Because only a few of you in your school will take part in this research, all testing will be done in one afternoon after school, to limit possible questions/interest from all the other children and their parents. If you have any questions about what it means to be premature, please let us know.

However, this study will not harm you in any way. It will take place at your school, your teacher and parents will be waiting for you when you're finished. If I see that you find some of the activities a bit difficult, then I will tell your mom to help you work on that. If you get hurt in any way or feel ill, then I will ask your mom to take you to the doctor.

***What are the benefits of taking part?***

The findings from this experiment will help us to understand how children especially those that are born too early, can be helped. It will also help hospitals and the education department to implement good care and education programs.

Making a cross in the box or writing your name means that you understand what I have told you and that you want to take part in my study.

**If you want to take part, sign this section**

Child's printed name: \_\_\_\_\_ ☐

Signature of tester: \_\_\_\_\_

Date: \_\_\_\_\_

**If you do not want to take part, sign this section**

Child's printed name: \_\_\_\_\_ ☐

Signature of tester: \_\_\_\_\_

Date: \_\_\_\_\_

**Assent form for full term participants (to be read out to participants by tester)**

The study will be explained to the children in an age appropriate manner and they will be given the opportunity to sign assent or to dissent. Assent will be obtained at the school after the families have been visited at their homes to explain the study to them.

**Request to participate in a research study:**

My name is Henriëtte Oosthuizen (Tredoux). I am a physiotherapist in private hospitals in Bloemfontein. I am writing a paper about children being born earlier than expected and how they compare with you that were born at the expected date. I have found your name from hospital records when you were a baby. Your parents gave me permission to ask you if you want to take part in a few activities and answer some questions about your life.

***Why do I want you to take part in this study?***

I want to find out how easy you find the activities/to watch how you do different things.

***What do you have to do?***

We will ask you to do some physical activities from a game (the *Movement ABC-2*). The activities will be familiar to you, it will include placing pegs, threading lace, drawing on a line, catching, throwing a bean bag, standing on one leg, hopping in squares and walking with your feet behind each other. You do not have to worry about reading the questions, a trained person will assist you and explain each question and activity to you so that it is clear to you. No one else will be able to see how you scored in the activities.

Furthermore will you also be ask to complete *the EQ-5D-Y* questionnaire about how you see your current health.

You will do the different activities and the questionnaire individually with the tester in the gym area, no other children will be there.

***What do the parents/guardians have to do?***

They will also be asked to fill in *Strengths and Difficulties Questionnaire for parents*. This questionnaire will tell us more about your feelings and emotions (happy, sad, and angry).

Your parents/caregivers will be completing the questionnaires in a classroom in the company of a different tester to assist them.

All the parents/caregivers will be completing the questionnaires in a classroom in the company of a different tester to assist them.

***What do your teachers have to do?***

Your grade R, 1 or 2 teachers play a big part in this study, since they are in contact with you a big part of the day and might experience you different from your parents/guardians.

Therefore they will be asked to complete the *Strengths and Difficulties questionnaire* about their experience of some of you in terms of behaviour and emotional difficulties. They will also be asked to complete the *Movement Assessment Battery for children's checklist* (MABC-checklist). This questionnaire will test your functional classroom and playground movement.

Your teacher will be in another classroom with a different tester, completing their set of questionnaires about you.

***When will these tests take place?***

All of this will happen after school hours in your classroom and the gym area of your school. All the questionnaire and activity tests will only take about an hour of your time. It will not prevent you from doing homework or taking part in sports or any other activities that you might have.

***How long will it take?***

Answering these questions will only take about 20 minutes. The physical activities will take about 20 – 40 minutes of your time.

***What happens after the tests?***

If we see that there are some areas that you find a bit difficult, we will inform your parents/guardians and we will make sure you get the assistance you need to help you overcome the problem.

***Who will know the outcome of the tests?***

Only your parents will receive the results of their child. It is their decision if they want to share the results with your teacher.

***Can you refuse to take part in this study?***

You are free to say no, even if your parents have already agreed.

Even if you start you can still stop at any time you want to, your teachers and I will not hold it against you. You may also ask any questions about this study.

***What about privacy?***

If you decide to take part in this study, I am not allowed to tell anyone what you said or wrote on your paper. Even if your parents, teachers or friends ask me what you wrote, I will not tell them. Participation to this study is completely your own choice; no one can force you to participate. You will not receive any money or gifts to take part in this study. Only your parents/caregivers will receive your results. It is their decision and discretion if they want to share the results with your teacher.

***What are the risks involved in this study?***

It may be distressing for you and your parents/guardians to learn that you are not performing well; therefore we will refer you to the school social worker or psychologist for counselling and support. You will be referred to another therapist to confirm what we found in the questionnaires and they will help you.

All testing will be done in one afternoon after school, to limit possible questions/interest from all the other children and their parents.

The researcher and the people that are going to help her are trained to help you understand what prematurity is and how it might affect you. If you are worried about anything, please let us know.

However, this study will not harm you in any way. It will take place at your school, your teacher and parents will be waiting for you when you're finished. If I see that you find some of the activities a bit difficult, then I will tell your mom to help you work on that. If you get hurt in any way or feel ill, then I will ask your mom to take you to the doctor.

***What are the benefits of taking part?***

The findings from this experiment will help us to understand how babies, especially those that are born too early, can be helped. It will also help hospitals and the education department to implement good care and education programs.

Making a cross in the box or writing your name means that you understand what I have told you and that you want to take part in my study.



**If you want to take part, sign this section**

Child's printed name: \_\_\_\_\_ ☐

Signature of tester: \_\_\_\_\_

Date: \_\_\_\_\_

**If you do not want to take part, sign this section**

Child's printed name: \_\_\_\_\_ ☐

Signature of tester: \_\_\_\_\_

Date: \_\_\_\_\_